Models of Access and Clinical Service Delivery for HIV Positive People in Australia

Final report

Prepared by
the Australasian Society for HIV Medicine
April 2009
Acknowledgments

This project developed from the concerns of people in the sector. It was funded by the Commonwealth Department of Health and Ageing and state and territory health departments. It has been a collaborative effort between the Australasian Society for HIV Medicine (ASHM) and the National Association of People Living with HIV/AIDS (NAPWA). They have been greatly assisted by the Models of Access and Clinical Service Delivery Advisory Group, chaired by Jonathan Anderson. We would like to thank all those who participated in the interviews and surveys that provided valuable data for this project. This final report was prepared by Jan Savage for ASHM. Stephanie McLean from ASHM provided the background papers on workforce and service mapping and deserves special thanks. Marina Carman led the paper on HIV populations in Australia for the Australian Research Centre in Sex, Health and Society (ARCSHS). Jan Savage prepared the papers on chronic disease and international and Australian HIV models. Thanks must go to the Steering Committee members Jo Watson, Peter Canavan and Levinia Crooks. Levinia also gave great support and leadership throughout the project.

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<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AFAO</td>
<td>Australian Federation of AIDS Organisations</td>
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<td>AGPN</td>
<td>Australian GP Network</td>
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<tr>
<td>AHOD</td>
<td>Australian HIV Observational Database</td>
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<tr>
<td>AHMAC</td>
<td>Australian Health Ministers' Advisory Council</td>
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<tr>
<td>AMS</td>
<td>Aboriginal Medical Service</td>
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<tr>
<td>ANF</td>
<td>Australian Nurses Federation</td>
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<tr>
<td>APHDPC</td>
<td>Australian Population Health Development Principal Committee of AHMAC</td>
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<tr>
<td>APNA</td>
<td>Australian Practice Nurses Association</td>
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<tr>
<td>ARCSHS</td>
<td>Australian Research Centre in Sex, Health and Society</td>
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<tr>
<td>ASHHNA</td>
<td>Australasian Sexual Health and HIV Nurses Association</td>
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<tr>
<td>ASHM</td>
<td>Australasian Society for HIV Medicine</td>
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<tr>
<td>BBVSS</td>
<td>Blood Borne Viruses and STIs Subcommittee of APHDPC</td>
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<tr>
<td>CALD</td>
<td>Culturally and linguistically diverse</td>
</tr>
<tr>
<td>CNC</td>
<td>Clinical Nurse Consultant</td>
</tr>
<tr>
<td>DoHA</td>
<td>Australian Government Department of Health and Ageing</td>
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<tr>
<td>EN</td>
<td>Enrolled nurse</td>
</tr>
<tr>
<td>GP</td>
<td>General practitioner</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly active antiretroviral therapy</td>
</tr>
<tr>
<td>HASTI</td>
<td>HIV/AIDS and STIs Subcommittee of the Australian Government Department of Health and Ageing</td>
</tr>
<tr>
<td>MACASHH</td>
<td>Ministerial Advisory Committee on AIDS/HIV, Sexual Health and Hepatitis replaced by MACBBVS (March 2009)</td>
</tr>
<tr>
<td>MACBBVS</td>
<td>Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmissible Infections</td>
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<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
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<tr>
<td>NAPWA</td>
<td>National Association of People Living with HIV/AIDS</td>
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<tr>
<td>NCDS</td>
<td>National Chronic Disease Strategy</td>
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<tr>
<td>NCHECR</td>
<td>National Centre for HIV Epidemiology and Clinical Research</td>
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<tr>
<td>NCHSR</td>
<td>National Centre for HIV Social Research</td>
</tr>
<tr>
<td>NP</td>
<td>Nurse practitioner</td>
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<tr>
<td>NPHCS</td>
<td>National Primary Health Care Strategy</td>
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<tr>
<td>QPP</td>
<td>Queensland Positive People</td>
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<tr>
<td>RACN</td>
<td>Royal Australian College of Nursing</td>
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<tr>
<td>RN</td>
<td>Registered nurse</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Introduction

This project arose from concerns about the impact of a range of changes to the human immunodeficiency virus (HIV) population and related HIV health workforce in Australia now and in the future. The report addresses the issue of providing HIV clinical services in the face of the anticipated change to the demographics and clinical situation of people with HIV in Australia. The number of people with HIV is increasing due to continuing occurrence of new infections and diagnoses and the increased life expectancy of people with HIV as a result of improved therapies. The pattern of HIV as a disease is changing too, as a result of medical advances. It can be viewed as a chronic condition, with an initial and brief acute component at the time of seroconversion, a protracted, asymptomatic stage with minimal therapeutic intervention and a period of more intensive and complex clinical intervention. Death may be related to HIV, to co-morbidities, to a combination of both or, of course, to unrelated events.

In Australia, the vast majority of people with HIV are men having sex with men (MSM). The majority of people with HIV are capital city dwellers and 88.2% (NCHECR 2008) live in New South Wales, Victoria and Queensland. The majority of people with HIV are English speaking from an Anglo-Australian background. The median age at diagnosis has increased from 32 years for men and 29 years for women before 1998 to 38 years and 32 years respectively in 2007 (NCHECR 2008). Service use is generally dependent on the models of service delivery that are geographically available. The majority of people with HIV are generally satisfied with the standard of the HIV clinical services they use. The HIV population in Australia is both ageing and living longer as scientific, medical and clinical progress enables the delivery of improved health outcomes. However, sub populations of people with HIV remain marginalised and vulnerable to poor health outcomes, particularly those from culturally and linguistically diverse (CALD) and Indigenous backgrounds, women, those with co-morbid conditions (particularly mental health) and people living beyond inner urban areas.

It is anticipated that this ageing HIV population like the non-HIV population will become increasingly dependent on income support and will move from the major urban centres with their concentration of HIV and non-HIV specific services (Grierson 2006, Gurran 2005, Hugo 2007).

Current models of HIV clinical service delivery used in Australia vary across jurisdictions, geographically and in response to the target group. They share a number of important principles: they value cultural and geographical accessibility; they are patient-centred, multidisciplinary, integrated and co-ordinated; they are based on strategic, co-ordinated and consultative planning; they feature effective and useable health information and communication technological systems; they recognise and support workforce strengthening, professional development and support and they are underpinned by evaluation and research.

The literature on chronic disease management outlines similar features of health systems, clinical information systems and delivery systems to respond to chronic and complex problems (including the workforce). There is little evidence about effective models of HIV access and service delivery internationally; however, there are recurrent themes of the importance of provision of free services and drugs, user-friendly hours and locations as well as the impact of
relatively higher levels of clinical experience with HIV and application of case management models.

As part of an international trend, the health workforce in Australia is undersupplied. Our health workforce is ageing, as is our population generally. This is particularly evident in nursing and medical sectors. While the problems of recruitment, retention and succession management have been identified, there are few effective, evidence-based interventions in place to address them. Additionally, there is a strong move towards specialisation and away from generalisation within these disciplines. There are barriers to change across all levels of the health system such as task substitution and delegation and difficulties with the application of enhanced primary care to HIV – and to relevant co-morbidities. The HIV-specific health sector does not appear to have identified potential problems that will have an impact on people with HIV and the need for additional or different recruitment, retention and training strategies.

These anticipated changes to the demographics and clinical situation of people with HIV in Australia call for adjustments or transformations in clinical service delivery to provide and maintain high standards of care for them. This paper will outline the background to the project’s development. It considers the demographics of people with HIV and maps clinical HIV services across Australia. It presents the various models of service access and delivery for HIV internationally and in Australia and models of chronic care applied locally and internationally. It describes the Australian health workforce and considers how it currently responds to the needs of people with HIV and the anticipated demands of this population in the future.

In preparing the background papers for this project, it became very clear that there was little evidence in the national and international literature to guide policy makers and funders. Where programs or interventions had been evaluated, the findings were short term and generally related to process, rather than linked to longer-term clinical outcomes. Not surprisingly, because of the specialised nature of this area, economic analyses of systems of service delivery, particularly local economic analyses, were absent. The settings of interventions described in the international literature were frequently quite different from those in Australia, so the evaluations were not easily generalisable to our situation. The report flags the likelihood of changes to the Australian health system, especially in the primary health care and preventative health sectors, with the ensuing workforce consequences. A number of the recommendations arising from this project appear to mirror the directions these health system reforms seem to be taking. The impact of the global financial crisis on health care reform and delivery is uncertain and a discussion of this aspect is beyond the scope of this report.

The final section of the paper presents and recommends demonstration projects that have been developed in response to issues identified for future models of access and clinical service delivery for people with HIV in Australia. These projects were developed and prioritised by the Models of Access and Clinical Service Delivery (MACSD) Advisory Panel and the project team. For the most part, they build on work that is currently underway. When implemented, the findings from these projects will inform, improve and maintain future HIV clinical service delivery.
Background to the project process and content

Background to the Models of Access and Clinical Service Delivery project

In Australia, the number of people living with HIV has increased steadily over the past decade (NCHECR 2008) and this trend is expected to continue. The longer life expectancy of people with HIV and advances in HIV clinical management are resulting in increases to the lifetime engagement of people with HIV with the health sector. There is increasing contact with a large number and wider variety of clinical and other health service providers. Continuing advances in HIV diagnosis, monitoring, treatment and prevention are creating additional complexity in clinical management. This then involves a wider range of clinical and other service providers, who, over a longer period, are managing increasingly complex clinical situations (unpublished report from the ASHM key informant workshop Nov 2007). At the same time, the profile of HIV services and service providers is changing partially in response to the change in the natural history of the treated infection, contributed to by general and HIV specific health workforce trends, attrition and inaction. Treatment needs are dynamic: the majority of people with HIV are moderately engaged with health services and the levels of involvement change in response to changes in therapeutic guidelines about when treatment should commence. People with HIV and HIV services are concentrated in inner urban areas – however these do not necessarily address the changing service needs of the population. Service access and delivery outside major cities and to other (urban) marginalised groups continue to be problematic.

The HIV clinical complexities forum 2006 (unpublished) reported that many aspects of Australia's health system serve people with HIV well; however, other areas of the health system require review and modification to meet the current and future changes to health needs. Improvement to clinical service access and delivery for HIV positive people is the key issue. The response focuses on models of clinical service delivery and workforce development.

The need for an updated response by health services and health care providers to the changing situation of people with HIV has been recognised for some time. For example, ASHM conducted a Think Tank in 2005 into the (emerging) needs of general practitioners (GPs) in New South Wales (NSW) to enter into the area of care, and to continue to provide care, for people living with HIV and viral hepatitis. Also in 2005, NAPWA produced a paper entitled *The impact of complexity on HIV clinical management and clinical research* (NAPWA 2005) which examined the increasing complexity of HIV clinical management and suggested broad areas of response. The report from the key informant workshop, conducted by ASHM in November 2007 (unpublished), has also directly informed the content of this report.

Nationally, forums such as the HIV Clinical Complexities Forum, November 2006, the Mid-term Stock take of the 2005-08 National HIV Strategy, February 2007 and the HIV Clinical Complexities Project Report of Joint Working Group, May 2007 were held from 2006. These identified and developed responses to the need for service change and recognised this need as a priority.

From these forums it was determined that:

1. efforts should be directed towards the development of models of access and clinical service delivery for HIV positive people living in Australia (MACSD), and that this terminology should henceforth be used.
2. all work on possible models should be nationally co-ordinated, multidisciplinary, multijurisdictional and multisectoral. It should encompass both the HIV sector and other mainstream health areas such as alcohol and other drugs, mental health, aged care and chronic care.

The models would describe ‘packages of care’ and support for people with HIV, including:

1. clinical care (including medical and the incorporation of prevention into clinical management), allied health care (including anything that is directly linked to medical care)
2. non-clinical care, such as referral to housing and financial support
3. models would likely be for different populations of people with HIV, recognising the differing needs of:
   a. those with highly complex needs
   b. certain population groups such as Aboriginal and Torres Strait Islander people and people from CALD backgrounds
4. descriptions of what is needed to maximise the health of people with HIV, ensuring that the right care is provided:
   a. at the right time
   b. in the right place
   c. by the right team. That is, workforce issues of recruitment, retention and training would be addressed.

The Models of Access and Clinical Service Delivery (MACSD) project arose from these discussions. It was identified as a key priority in the National HIV/AIDS Strategy 2005-2008 (Australian Government 2005). The Blood Borne Viruses and STIs Subcommittee (BBVSS) of the Australian Population Health Development Principal Committee (APHDPC) endorsed this project which is jointly funded by the Commonwealth, States and Territories. Contracts were signed with the Commonwealth at the end of July 2008.

The aims of the project are to evaluate and update the current models of access and clinical service delivery for HIV positive people living in Australia. The results of the evaluation will inform any changes required for models of future care, including workforce capacity and education.

The stated objectives of the MACSD project are:

1. to identify HIV workforce issues and develop a plan to address any current or anticipated deficiencies; and
2. to ensure that the outcomes of the project can inform policy activities and future programs undertaken at national, state and territory levels of government. The project will guide health care workers and community organisations, including ASHM, in improving service delivery to HIV positive people in Australia.

The expected outcomes of the MACSD project are (from the Commonwealth Standing Funding Agreement 2008):

1. development of a framework for strengthening the delivery of HIV clinical service and the clinical workforce capacity of Australia’s HIV/AIDS response. This framework will
incorporate best practice and quality standards, appropriate treatment and prevention (including secondary and tertiary prevention methods);

2. identification of existing and potential opportunities for peer education and support resources for patients, carers and community services in Australia;

3. updating models of access to care to improve the quality of life for people with HIV living in Australia;

4. establishment of a high level implementation strategy for the revised models of access to service delivery and care, including a plan for workforce development at the national level provided to BBVSS for consideration by the Australian Health Ministers’ Conference. This strategy must be flexible and adaptable for use by each State and Territory; and

5. submission of regular progress reports to the Commonwealth Department of Health and Ageing.

The scope of the MACSD project (Standard Funding Agreement 2008, BBVSS minutes 2008, HIV Clinical Complexities Project, Report of Joint Working Group Meeting, May 2007) is to:

1. conduct research and analysis, covering both national and international sources, to inform work

2. define principles and standards that will underpin any future HIV models of access

3. draw on the principles and standards identified in (2), define the desired models of HIV access and clinical service delivery for various HIV positive populations in Australia and

4. identify workforce capacity issues in relation to the new models of access and determine a strategy for how these will be addressed.

Finally, the project activities were defined:

1. Review the current models of HIV clinical service delivery to determine if they meet the needs and health care demands of people with HIV. This review will be in the context of the complex and diverse nature of HIV care and increasing HIV caseloads, particularly in relation to issues identified in the Report of the HIV Clinical Complexities Forum – ‘Health System Issues and Challenges in Complex HIV Care’. unpublished

2. Map existing HIV clinical services, general practitioners, Section 100 prescribers and HIV-positive populations. Provide an analysis of these data including gaps in the information available.

3. In consultation with people with, and affected by, HIV, and health services providers, identify effective models of HIV clinical service delivery operating in Australia and overseas which could have wider applicability in delivering HIV clinical care in Australia.

4. Identify any aspects of Australian and overseas models of clinical service delivery in other chronic disease areas which could enhance the delivery of HIV clinical care in Australia.

5. Provide advice for the improvement of current care models to inform policy, research and service delivery. This advice will be provided to Commonwealth, state and territory governments (through the BBVSS) as well as the community sector through the Australasian Society for HIV Medicine’s (ASHM) website.

6. Review skills, experience and training needs for advanced, intermediate and basic HIV care, including the use of antiretrovirals and medicines for HIV-related conditions, in relation to future models of access and clinical service delivery.

7. Following the development of the new models of access and clinical service delivery, review the workforce capacity to project the future needs of hospital, sexual health clinic and
general practice based HIV care. Refer to the Report of the HIV Clinical Complexities Forum – ‘Health System Issues and Challenges in Complex HIV Care’ (unpublished) and findings of the discussion papers produced as part of this project.

8. Provide a detailed work plan for this project including high level budget expenditure and work allocations.

9. Provide the Commonwealth with a minimum of three and up to six discussion papers that outline principles, standards, data analysis and evidence on the effectiveness of the current and future HIV models of care, access and clinical service delivery, including capacity, deficiencies and adaptability to the changing nature of HIV.

The Australasian Society for HIV Medicine and the National Association of People Living with HIV/AIDS (NAPWA) were contracted by the Commonwealth Department of Health and Ageing (DoHA) to undertake this project. They were overseen by an expert Advisory Group. This was chaired by Dr Jonathan Anderson from the National Centre in HIV Epidemiology and Clinical Research (NCHECR) The membership of the Advisory Group was required to comprise ‘at the very least, representatives from BBVSS, the (former) HIV and STI committee of the (former) Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis, and HIV clinical experts’. Further details, including the terms of reference, of the Advisory Panel are included in Appendix 1.

The results of this project are comprehensive research papers which provide a solid evidence-based platform for further work in the area of HIV service access and delivery in Australia. Papers have been prepared on the following topics:

- HIV populations in Australia
- Existing HIV services across Australia
- Models of HIV access and clinical service delivery used in Australia
- International approaches to access to and clinical service delivery for people with HIV
- Models of care for chronic disease (nationally and internationally)
- Australia’s health workforce: its capacity to respond to changes in HIV

The methodology was varied. It comprised literature reviews, questionnaires and interviews (by telephone, email or face-to-face) and specific requests for unpublished data.

The project has responded to many issues and raised many more questions. The resulting demonstration projects highlight the demand for continued collection of information, research and evaluation in the area. The present project must be placed in a strategic framework or context giving consideration to the demands arising from current health, social and economic change and pressure both in Australia and internationally.

**HIV populations in Australia: implications for access to services and delivery**

The Australian Research Centre in Sex, Health and Society was commissioned to provide a report which described important features of the HIV population in Australia that related to social determinants of health, health and wellbeing, experiences of HIV now and in the future, barriers to health service access and achieving health outcomes and changes to the current models of HIV clinical service delivery in the short, medium and long term (Carmen 2009). This report also focused on attributes of HIV subpopulations and their health care needs.
The key points that ARCSHS presents relate to population trends (increasing rates of HIV, life expectancy, co-morbidities and geographical change and differences), service demands (HIV treatment, access to antiretrovirals, medical services and gaps and barriers), key subpopulations (priority populations, people who have lived with HIV for a long time, those with newly acquired infection and late presenters), HIV and socio-economic disadvantage (economic, social, cultural and geographical features) and projections for service change and implications for future research.

The report highlights these following areas: the population of people living with HIV in Australia is growing. The rate of newly diagnosed cases continues to increase, as does the proportion of newly diagnosed individuals with recent acquired infection (NCHECR 2008). The number of AIDS cases remains steady (and therefore becomes a decreasing proportion of all cases of HIV). The age at HIV diagnosis is increasing (from 31 in 1998 to 35 years in 2002 in men and 19 to 37 years for women for the same period (NCHECR 2008)). People with HIV are surviving longer and their average age is increasing.

With treatment, the median survival time is estimated at over 32 years after diagnosis (Lloyd-Smith 2006, Antiviral Therapy Cohort Collaboration 2008). New antiretroviral regimens have had major impacts on the health of those with HIV; as well as affecting disease progression, they have also had an effect on health maintenance and consequent financial and psychosocial status. There is an increased emphasis on managing side effects of treatment and long-term toxicity, as well as co-morbidities related to ageing and lifestyle. The mental health demands of people with HIV are also emerging as significant. Many of these conditions go beyond the areas of familiarity for health service providers; the non-HIV specialist however generally has limited experience with HIV as a co-morbidity in their own speciality.

There are jurisdictional differences in rates of HIV. NSW, with the majority of cases nationally, has a fairly stable rate of new HIV cases, while increases are reported in most other states, particularly Victoria and Queensland. Although the majority of people with HIV live in capital cities, centralised to inner urban areas, there are significant minorities who live in regional centres or, less commonly, rural and remote areas. The trend of retiring Australians (baby-boomer generation) to leave city areas has been well documented (Gurran 2005). People with HIV may follow these trends with the consequent pressure on non-urban health services.

Among people with HIV, there are three main categories relevant to medical service demands: those not on antiretrovirals, those who are stable on treatment, and those with complex treatment demands. The number of people overall on treatment has steadily increased, with the recent Futures 5 study reporting an estimated 75.5% of those sampled on therapy (Grierson 2006) and increasing proportions with undetectable viral loads (Falster 2008). Although this result is encouraging, approximately 20% reported having been diagnosed with an AIDS-defining illness; and 30% of respondents reported HIV-related illnesses, with a large proportion indicating they had experienced fatigue, diarrhoea and sleep disorders in the last 12 months (Grierson 2006).

Service demand varies across different groups of people with HIV. A minority of people with HIV (25% in the Futures 5 study) are not currently on treatment - although 40% had been (Grierson 2006). The majority of people with HIV who are relatively stable on treatment are accessing antiretroviral therapy through HIV GPs or HIV specialists. Meanwhile, the small group with
complex treatment demands require specialist care (provided mostly by HIV specialists, either physicians or high caseload GPs) and occasional acute inpatient or ambulatory care. This last (complex) group with co-morbid conditions also need to access other non-HIV services such as mental health services and their complexity requires a higher level of management by their primary care giver, for example the development of care plans and accessing and coordinating service delivery.

Access to prescriptions for antiretroviral and other drugs varied according to the availability of pick-up points, and across area type – capital city/inner suburban, outer suburban, regional centre, and rural, as well as by state or territory. Similarly, access to HIV-related health management rather than general health care varied across states and territories, and across area type. HIV GPs were the single most common source of HIV care (43.2%) and general medical care (46.7%), followed by HIV specialists (32.8%) who also provided 13.8% of general care. Other GPs were used for 4.4% of HIV care and 25.1% for general care. In Queensland, HIV care is more likely to be provided through a sexual health centre than by an HIV GP and in Western Australia it is more likely to be provided through an HIV outpatient clinic.

Generally, those in the outer suburbs were least likely to attend an HIV GP and instead attend sexual health clinics; inner suburban dwellers attended HIV GPs. People from the outer suburbs were also the least likely to visit an HIV GP for general health care.

Other service demands of people with HIV are significant, and services are accessed through both HIV community organisations and other organisations and services. NAPWA (2007) noted that after medical care, most demands related to income support, housing and employment which were accessed through mainstream and HIV-specific services. One third of respondents in the Futures 5 study (Grierson 2006) described unmet needs for services such as peer support groups, financial assistance and services beyond the inner suburban areas of capital cities. Other areas of need are mental health and counselling services, oral health services and specific supported accommodation.

Looking at service access and delivery requires a particular approach to characterisation of key sub-populations as the focus is not simply on analysing populations at risk but on the nature and shape of specific interactions and interventions. In the paper, key sub-populations are identified based on the duration of infection and stage of illness when diagnosis was made. These sub-populations are: people living with HIV long term (mostly gay and homosexually-active men); those with newly acquired infection (mostly gay and homosexually-active men), and late presenters (particularly from culturally and linguistically diverse backgrounds). Importantly, general patterns can be determined from how underlying health, social, cultural and economic issues interrelate with service demands in these sub-populations. The pattern encompasses the diversity that may be missed when using traditional priority groups such as those defined in the National HIV Strategy (Australian Government 2005): gay and homosexually-active men, Aboriginal and Torres Strait Islander people, people who inject drugs, people in custodial settings, sex workers, and people from culturally and linguistically diverse backgrounds. This prioritisation is particularly useful when considering prevalence and transmission, but has less application in understanding service need and use.

HIV GPs and specialists predominantly meet care demands for the gay and homosexually-active male population of people living with HIV long term, and access to these people has
historically been facilitated by the geographical location of much of this population. However, this population is increasingly marked by the complexities associated with ageing and a range of treatment, health care and other service demands. In terms of other groups within the population of those living with HIV long term, treatment, health care and support demands may differ slightly. Women, for example, are estimated to make up only 8% of the population, but have specific demands in relation to long-term HIV infection.

Male homosexual contact was the transmission factor identified in 82% of cases of newly-acquired HIV 2003-2007 (NCHECR 2008). This population of gay and homosexually-active men tend to live in inner urban areas. Relatively, they are younger and healthier than those living with HIV long term. However, they require additional support to cope with new diagnosis, including peer support, education and counselling.

This population with newly acquired infection is more likely to include people who are not on treatment. However, medical service demands will be high due to the initial clinical consultations and assessment including laboratory and other diagnostic investigations and testing and possible treatment initiation. Care is likely to be provided predominantly by HIV GPs and specialists, as the geographical location of this population is again likely to match the overall demographics of homosexual and bisexual men.

Late presentation is an important and growing issue for service delivery. A large percentage of late presentation is related to heterosexual transmission. In 2003-2007, 60% of cases of HIV infection attributed to heterosexual contact involved people from high-prevalence countries and their partners. The communities of concern vary by state. In Victoria, the focus has been on those from the horn of Africa (Sudan, Somalia, Ethiopia and Eritrea), Arabic-speaking and Vietnamese communities (McNally 2006). In NSW, Cambodian and Thai communities have been a focus. While the experiences, current circumstances and location, and thus demands of these communities vary, there are some commonalities.

This CALD population is more likely to be socially and economically disadvantaged. Geographically, although there are some exceptions, the CALD population is quite dispersed making access to HIV-specific services more difficult. It also highlights the need for HIV experience and expertise outside of these HIV-specific services as late presenters tend to be diagnosed outside HIV-specific services. Diagnosis usually occurs when they become ill or are seen when pregnant. There are some similarities between the issues facing the CALD population and Aboriginal and Torres Strait Islander people, particularly in terms of the interaction of HIV infection with existing health disparity, other economic and social disadvantage, and relative geographical isolation and cultural differences which may limit access to appropriate and effective services. Late presentation is also a feature of HIV diagnosis in this group.

While socio-economic disadvantage may not be an issue for everyone at the time of diagnosis (apart from late presenters in CALD or Indigenous populations), there is evidence that it may become so over time (Grierson 2006, 2007). Stress over financial issues also compounds the adverse health effects of HIV (Grierson 2006, 2007). The general disadvantage is complicated by place of residence and access to transport, as people may move to more affordable areas that do not offer the same service range, and then have to manage the financial impost of transport and travel.
Social and cultural issues have an effect on physical and emotional wellbeing as well as on service demand. The significant factors that have been reported in Australia include engaging in health improvement strategies (including social engagement), not living alone and the effect of stigma and discrimination on access to social support and other services.

The paper concludes that ‘two important emerging issues are potential changes in the patterns of geographic location of the HIV-positive population, and changes in how and what type or style of services are accessed or wanted. ... The key issue remains tailoring medical and other service delivery to individuals. This will require a balance between expanding access to mainstream services, and developing or supporting the capacity of HIV-specific services in particular areas. ... Further research is required in relation to emerging trends and projections in the HIV-positive population, and the implications for service planning and delivery (Carmen 2009).’

**Existing HIV clinical services in Australia**

Access to HIV clinical services has been reported as being problematic at times. ASHM examined the HIV health services provided across Australia and prepared the background paper (McLean 2009a). The objective of the report is to map the clinical services available to people with HIV across Australia. The services will be defined geographically and described on the basis of the services they provide, the service model used and the staff who provide these services. It includes preliminary work which defines the postcode for newly diagnosed cases of HIV nationally for 2007-2008. This report therefore provides a comprehensive review of existing clinical services in Australia.

The blood borne virus (BBV) and sexual health programs (or their equivalent) in each jurisdiction were contacted to provide local data and insight into their HIV models of access and service delivery. The results presented are a composite of these responses and information from other sources such as annual reports, strategic plans and departmental HIV Models of Care.

Appendix 2 summarises the text below in maps of the various HIV services across the country.

**Sexual health services**

Publicly funded sexual health services exist in all states and territories. These facilities may operate as public hospital outpatient services or as stand-alone public clinics (Victoria and Northern Territory). While some clinics are open full-time, many smaller regional clinics, where they do exist, provide only part-time or sessional services. Medical specialists in sexual health, infectious diseases, public health and immunology and specialist GPs staff these clinics. Medical and nursing postgraduate trainees and undergraduate students also attend. The professional interest, expertise and training of nursing staff are similarly wide. Many have further training in HIV, sexual and reproductive health or public health. A model of multidisciplinary care is usually employed in the larger clinics with the addition of staff from other disciplines such as psychology, social work, community work and nutrition.
General practitioners

The roles of general practitioners (GPs) in HIV care, or non-HIV management of patients with HIV are increasing. A significant minority of all new cases of HIV are diagnosed by non-HIV experienced GPs (Ward 2008, Stoove 2008). Low case load GPs experience difficulties in maintaining their skill base and keeping up to date, accessing and participating in HIV training and accessing specialist support or advice.

GPs with S100 prescribing rights are most frequently consulted for HIV and non-HIV problems (56%) (Grierson 2006). Outside metropolitan areas there is a shortage of S100 prescribing GPs and of GPs involved in HIV care generally. This situation varies between jurisdictions. The result is that people with HIV in rural and remote areas may have to travel significant distances to access care. There is limited HIV service delivery by GPs in Aboriginal Medical Services. Although it is difficult to generalise, a guarded conclusion in the background paper is that individuals from CALD backgrounds tend to access sexual health services or outpatients rather than local GPs. Slightly more than half of S100 community GP prescribers are in NSW, nearly 20% are in Victoria and 13% are in Queensland (from states and territories 2009) (McLean 2009a).

Specialist HIV services

All major cities have specialist tertiary hospital-based HIV services (with the exception of the Northern Territory where hospitals provide inpatient care only and all ambulatory care is managed through sexual health services). HIV specialists are defined as the most important source of HIV treatment and management after S100 GP prescribers. There is a strong network between hospital specialist services and S100 GP prescribers. The proportion of HIV patients seen in these outpatient services varies according to the state or territory model.

People in rural or remote areas access specialist services by visiting medical providers, patient travel to urban site, or shared care with GP, sexual health or public health practitioner, again according to the local model.

Aboriginal community controlled health services

Aboriginal Medical Services (AMS) are not defined as centres that provide HIV treatment and care. There are issues of confidentiality and stigmatisation associated with these services, as well as the concerns of practitioners about their lack of an HIV clinical skill base. However, in providing sexual health prevention and treatment, AMS have a key role in testing members of priority groups for HIV.

International approaches to access and delivery of clinical services for people with HIV

ASHM prepared a background paper that reviewed the international literature on the wide range of models used to improve access to and delivery of clinical services for people with HIV (Savage 2009a). These models exist in a variety of contexts: social, political, economic and cultural with varying priority populations and sub-populations. The evidence base is scant; there is little in the way of evaluation, and generally process was measured rather than HIV related health outcomes. Assessment is further hampered by the lack of standard definitions, for
example commonly used and understood service types, standards of care or goals; much in the literature remains implicit.

Service access is dependent on the relationship between many factors such as service existence, consumer qualities, knowledge and behaviour and wider social determinants. There are few data on the impact of clinical service access on health outcomes. The major findings from the literature are summarised below.

A Cochrane Collaboration review found mixed results (Handford 2006). It concluded that ‘it is difficult to draw conclusions for practice …but there are enough promising findings to indicate that multidisciplinary and multi-faceted treatments, health information system and hours of operation (evening and weekends) should be considered when designing health services and should be research priorities. …but evidence about their effectiveness is lacking’. Studies from developing countries found that free services and drugs are associated with improved virological outcomes and survival (Souteyrand 2008). Distance to services, perceived quality of care and drug availability appear to be determinants of service use (Kiwanuka 2008).

In the United States of America, free or subsidised services and convenience of use were associated with increased service use. A number of studies noted the apparent importance of patient-centred care, particularly with hard-to-reach clients or those from different ethnic background in increasing the engagement with services (Neville 2003, Korthuis 2008). The impact of fee for service was supported by a review of primary health care (Lewin 2008). User fees were found to reduce the use of necessary (as well as unessential) health services and drugs, thereby further disadvantaging poor populations.

The aim of the Cochrane Collaboration review (Handford 2006) was to assess the evidence regarding activities at the health service organisational level that improve health care for people with HIV. The evidence available for the review was limited and comparisons were difficult because of the small number of studies on each intervention and the lack of standard terms and definitions. The Cochrane Collaboration review reports that services (hospitals, wards and clinics) that see high volumes of patients with HIV have lower mortality rates (Handford 2006) however the studies used in the review provide no information on trends or biases to help explain this observation. Services which were involved in clinical trials had higher rates of highly active antiretroviral therapy (HAART) use but, again, no data on potential confounders such as patient volume or prescriber expertise were given.

In the review, the service model of case management was associated with decreased mortality, increased use of HAART and increased entry, increased and continuation of medical care (Handford 2006). One multidisciplinary service showed an association with increased uptake of antiretrovirals; another showed improved primary health care attendances; and a third noted that patients in a multidisciplinary care team were more likely to have more care and more consultations than those who were not linked. Services with health information systems (attributes were not recorded) in place noted increased use of HAART and prophylaxis and shorter hospital stays in patients whose doctors had received professional communications about patient care.

The United Kingdom and Hong Kong apply models that are reliant on centralised public health services and HIV clinical (medical) specialists (BHIVA 2007, Scientific Committee on AIDS
Patients in the UK are registered with GPs to provide primary health care. A multidisciplinary team approach, easy access to quality clinical care and services, a continuum of prevention and care, integration of care and public health prevention, and promotion of community involvement are the planks of the system of HIV care in Hong Kong. There is no reference to the primary health care sector in this system.

The New York State Department of Health provides a comprehensive range of HIV clinical and support services from prevention to hospice care. Within the model, there are different services available for individuals at different stages in their illness and for those coping with non-HIV issues that may affect their health outcomes. It uses a variety of models applied to different settings: multidisciplinary inpatient and outpatient care, case management, integrated preventative care, primary health care and co-location services such as drug and alcohol, youth or reproductive health issues. There is an overarching coordinating framework that involves community-based organisations, health care providers and HIV health services consumers. In New York, as in the UK, there is emphasis given to support programs that deal with housing, communication and community follow-up and non-medical issues that improve health outcomes (Cameron 2009).

Canada has a national HIV care strategy which includes features of comprehensive, multidisciplinary health service for those with HIV. The Canadian literature on HIV health service delivery to non-urban areas has little, however, to offer about services that may be applicable to rural and remote Australia.

From the literature, the majority of common themes to emerge are based on chronic care management models (Wagner 1998, Barr 2003), on elements of comprehensive primary health care and on an understanding of the importance of non-medical determinants of health. These common themes are:

- patient-centred care
- continuity of care and a continuum of care
- self management
- case management
- integrated, multidisciplinary team based approaches
- coordinated delivery system
- response to social determinants (housing, employment) and the importance of support services
- effective information management system.

Finally, it is important to note that our search revealed that sometimes the evidence simply does not exist or cannot be found in the forms that are required for our purposes. There is very little evidence that supports the implementation of programs or that guides decisions about the preference of one program or service delivery model over another. The majority of models appear to have been developed from existing models within an unwieldy health system. There are few data on the effectiveness of different models and none on cost effectiveness at a service level. There are no data that inform decision making about the sustainability of particular models. For those models that target marginalised populations, there is frequently a history of the delivery of pilot programs. These scenarios are not unfamiliar in our own health settings. Very few of the studies that are available consider the effect of engagement with clinical
services and health outcomes. The studies where outcomes are considered generally have diverse endpoints making conclusions difficult.

Additionally, the applicability of these findings to the developed world in general, to Australia in particular and to specific groups in Australia should be considered. What are the similarities and differences between our populations, the effect of our geography and demographic patterns and our health systems and those of the international studies? How well can we apply these findings and what are they assumptions we make and risks that we take in doing so? Interest in the application of any of these models in the Australian context will require further investigation to determine how suitable they are and to assess the likelihood of producing successful outcomes in an efficient way with our populations and sub-populations.

Models of access and clinical service delivery for people with HIV in Australia

ASHM prepared a background paper on the range of models used to provide accessible HIV clinical services across the country (Savage 2009b). All states and territories endeavour to provide targeted HIV clinical services that are responsive to client need and are staffed by a trained and supported workforce. NSW, Victoria, Queensland, South Australia and Western Australia have developed HIV service delivery models, models of care, HIV care plans (NSW Health (2005) VIC Department of Human Services 2008, RPR Consulting 2007, Department of Health WA 2008). There are no formal service delivery models in Tasmania, the Australian Capital Territory or the Northern Territory. It has been recognised that with the advances in HIV treatment there is a shift in focus from hospital-based to ambulatory care, and that HIV disease will make similar service demands to other chronic conditions. This shift in focus is managed differently in the jurisdictions with factors such as client load, specific client needs (duration of infection, co-morbidities, ethnicity, gender), availability of HIV specialists (GP and physician), geography and physical access, confidentiality and service types available (such as sexual health clinic, S100 prescribing GP, nurse practitioner, shared care hospital outpatients).

The jurisdictions overall recognise:

- the shift to ambulatory care
- the increasingly complex management required for people on treatment
- the need for planning, coordination and integration of services
- the problems generated by inadequate information systems
- the disadvantages of inadequate monitoring and evaluation
- the need for an adequately staffed, trained and supported workforce – particularly in times of change.

In response, in most jurisdictions, models have been applied that:

- will respond to the geographical HIV prevalence
- will re-orient services according to need
- are integrated and coordinated (with other HIV or specialised services and with mainstream services), and to that extent include shared care
- improve access of a service to more clients or to particular target groups
- are patient centred, holistic and comprehensive
- are multidisciplinary
• emphasise self management and provide a continuum of care including case management until the end-of-life
• address complexities associated with co-morbidities and ageing.

The models all highlight the importance of workforce management, addressing the mal-distribution of S100 prescribers and patients, the recruitment and retention difficulties for S100 prescribers and clinicians (medical and nursing) with an interest in sexual health and HIV and the importance of ongoing training and support for (medical and nursing) clinicians. It is recognised that the development of clinical guidelines and clinical pathways will support the non-specialist to provide some level of HIV care.

Another area that is recognised as an essential component of comprehensive HIV care is the provision of non-clinical services such as support with accommodation, employment and financial services.

User-friendly, current and effective health information systems underpin the success of these models. These information systems enhance clinical management and communication with other providers and facilitate data extraction to improve the monitoring process and outcomes.

It is clear that the access and clinical service delivery models developed and applied in the jurisdictions have drawn from the chronic care model (see below) of Wagner (Wagner 1998). The results of evaluations will be awaited with great interest by the health sector and HIV community.

Models of care for chronic disease

The paper prepared by ASHM (Savage 2009c) introduces the models of care for chronic disease that are employed in Australia and briefly looks at international models of chronic care management.

A World Health Organization (WHO) report encapsulates the problem for chronic health conditions and the service delivery response, where the focus has traditionally been on addressing acute health problems:

Health care for chronic conditions inherently is different from health care for acute problems, and in this regard, current health care systems worldwide fall remarkably short. Health care systems have not kept pace with the decline in acute health problems and the increase in chronic conditions. In fact, health care systems have not noticeably evolved beyond the conceptual approach used in diagnosing and treating acute conditions. The acute care paradigm is pervasive and now permeates the thinking of decision-makers, health care workers, administrators, and patients. The acute care model drives the organization of care throughout the world even today, even in the most economically developed countries.

To address the rising rates of chronic conditions, an evolution in health care systems is imperative, and they have to advance beyond the acute care model. Acute care will always be necessary (even chronic conditions have acute episodes), but at the same time health care systems must embrace the concept of caring for long-term health problems. Patients, health care organizations, and decision-makers have to recognize
the need to expand systems to include new concepts. Decision-makers are instrumental in facilitating a shift in thinking about health care. (WHO 2002)

There are many aspects of HIV disease which allow it to be categorised as a chronic condition. Australia is facing a major increase in the incidence of chronic disease with estimates that nearly 50% of all deaths and 80% of all disability will result from chronic conditions (AIHW 2006); increasing to 75% of all deaths by 2020. The features of chronic diseases, which could prompt common service responses, have been described as (AIHW 2006):

- having a complex causality, with multiple factors leading to the disease onset
- having a long development period, some of which may have no symptoms, although acute stages are described
- having a prolonged course of illness, perhaps leading to other health complications
- having an associated functional impairment or disability
- having an indefinite duration, generally never cured
- being one of the commonest causes of premature mortality and mortality.

The following classification of chronic conditions (NSW Department of Health 2004) helps in understanding their impact at a personal and community level and the varying service need and demand over time:

- non-fatal, non-communicable chronic disease (eg arthritis and musculoskeletal disease)
- serious, eventually fatal, non-communicable chronic disease (eg heart failure or cancer)
- persistent, communicable diseases (eg HIV).

Chronic disease is more prevalent in marginalised and disadvantaged sectors of the community such as elderly people, Indigenous Australians, those who are socially and economically disadvantaged and people with physical and intellectual disabilities or mental illness. This distribution highlights the complexities associated with a response to chronic disease and identifies the presence of co-morbidities in those with a chronic condition. The role of social determinants in the development and progress of these conditions and their impact on service access and use cannot be ignored.

A National Chronic Disease Strategy (NCDS) with National Service Improvement Frameworks has been developed for five areas of chronic disease: asthma; cancer; diabetes; heart, stroke and vascular disease; and osteoarthritis, rheumatoid arthritis and osteoporosis. It is clear, from the brief summary of the strategy below, that there are parallels with these conditions in the management of HIV.

The objectives of the NCDS are for a trained and supported health workforce to provide a continuum of interventions from prevention to clinical management to end-of-life care to maximise the wellbeing of those with chronic disease, their family and carers. Of the four key action areas, three are of immediate interest to the area of HIV access and clinical service delivery:

- early detection and early treatment
- integration and continuity of prevention and care
- self management.
Within the NCDS, general practice supported by a multidisciplinary team approach is presented as being central to chronic disease health service delivery. Its essence is planning, coordination and communication between health professionals and patients. The key implementation areas for this strategy are:

- building workforce capacity
- developing and strengthening strategic partnerships
- making progress with infrastructure and information systems
- enhancing investment and funding opportunities.

There is a separate National Action Plan on Mental Health, 2006-2011 (COAG 2006) which addresses the health needs of those affected by mental illness. Aspects of this plan relate to the provision of services to those with chronic health conditions and are relevant to people with HIV and mental health co-morbidities. Aspects of the mental health action plan are familiar such as patient-centred care, various levels of care and intervention and the importance of planning, coordination and communication between health providers, patients and carers.

The National Primary Health Care Strategy (NPHCS) is still under development (Australian Government 2008). Its stated priorities include:

- better rewarding prevention
- promoting evidence-based management of chronic disease
- supporting patients with chronic disease to manage their condition
- supporting the role GPs play in the health care team
- addressing the growing need for access to other health professionals, including practice nurses and allied health professionals like physiotherapists and dieticians
- encouraging a greater focus on multidisciplinary team-based care.

A number of these priorities align themselves very closely with those of the NCDS, and with existing models of HIV service delivery. These priorities will be an integral part of HIV service delivery: the management of HIV will need to be considered in the development of the primary health care strategy. The NPHCS discussion paper was released in late 2008. While there was much to be recommended generally in the proposed approach to an enhanced primary health care system, the following concerns were outlined in the ASHM submission (2009), endorsed by NAPWA, the Australian Federation of AIDS Organisations and Hepatitis Australia, to the Primary Health Care Strategy background paper 2009:

a) the concepts of primary health care generally reflected in the document are insufficiently broad
b) there is a need for greater consideration of and response to the social, economic and cultural determinants of health, as they relate to primary health care access and delivery
c) the scope of the strategy, in so far as the discussion paper focuses on general practice or appears based upon a predominantly medical model and should be broader
d) the issues associated with the management of complex, chronic clinical conditions within the primary health care system and by secondary and tertiary providers and agencies are insufficiently developed
e) prevention models have not been given adequate weight, especially when considering the epidemic of preventable chronic disease
f) the health workforce is an area of great concern and need and requires further discussion and more solid strategic proposals

g) training and professional development is a concern generally and regarding HIV specifically. Training with any new strategy does not just involve education about health topics but also very importantly about proposed changes to professional roles, for example, training and support in being part of a multidisciplinary (or interdisciplinary) team or being an effective case manager

h) communication - within the primary health care sector, and beyond. There must be an acknowledgment of the importance and strength of specialists and specialist and acute services and the roles in improving health outcomes through primary health care. Communication is so regularly raised as a barrier to effective service access and delivery that improvement must become part of the health system culture.

All the states and territories have their own chronic diseases strategies (with the exception of Tasmania which is in the process of developing a chronic disease strategy). There is broad agreement about the objectives of the strategies and the key action areas which are summarised here (NSW Health 2008).

Objectives:
- To improve the quality of life of people with chronic and complex conditions, their carers and families
- To prevent unplanned and avoidable hospital admissions.

The key action areas:
- Patient-centred care
- Empowerment
- Equitable, timely access
- Coordinated and integrated care
- Supportive organisational, governance and leadership structures
- Improved workforce capacity generalist and specialist
- Monitoring and evaluation
- Self-management
- Health information systems
- Continuum and continuity of care
- Proactive management
- Effective partnerships and planning
- Effective management of the acute-chronic interface
- Application of evidence-based clinical care (and service systems)
- Research
- Effective communication.

The figure in Appendix 4 from the Victorian Hospital Admissions Risk Program (DHS VIC 2004) schematically represents the approach to chronic and complex care management at a service model level.

The original Chronic Care Model developed by Wagner (1998) has undergone modification and revision although the key features remain (see Appendix 4):

- self-management
- decision support using evidence-based guidelines
- delivery system design to ensure that patients get the correct care delivered in a coordinated fashion by well informed professional health team members
- clinical information systems which efficiently support all aspects of care of people with chronic illnesses, including quality records, follow-up, recall
Aspects of the Chronic Care Model have been widely evaluated (Jeon 2008). Not all evaluations have been positive (Jeon 2008, Gillespie 2008). In particular, interventions targeting patients with low health literacy, telephone-based case management or those with limited funding and inadequate standards and guidelines for implementation resulted in poorer outcomes. Other studies have shown that health outcomes in chronic disease can be improved when implemented through a primary health care-led model (Beaglehole 2008). WHO provides a general framework to support the implementation of chronic care models (WHO 2002).

The national and international strategies draw heavily on the principles first outlined by Wagner (Wagner 1998). There are many similarities to these first principles in the approach to chronic conditions used in Australia. There is an evidence base of the many strengths of this model (and its variants) and findings that define its shortcoming. The review of international models of HIV care identified difficulties in generalising findings to the Australian setting. Equally, there may be difficulties in applying chronic disease programs developed overseas to the Australian context and more particularly to the Australian HIV context. However, there is much that is being applied successfully, which warrants further consideration in the management of HIV as a chronic condition.

**Australia's health workforce: its capacity to respond to changes in HIV**

In this background paper (McLean 2009b), ASHM reviewed the capacity of Australia’s health workforce to address HIV and respond to future changes in service need. The sections of Australia’s health workforce that deal with access to and delivery of HIV clinical services comprise a wide variety of professionals. Doctors range from generalists to specialists, those in training or fully skilled, those with an interest in HIV, those with little experience or those who are fully immersed in the area. Equally, nurses participate in the primary health care sector – either in general practice, including as a practice nurses, or community centres. They may be highly experienced and trained nurse practitioners or nurse specialists undertaking dedicated HIV work in clinics and hospital settings (inpatient and outpatient). As with medical staff, there is the opportunity for on-the-job training and further study for nurses. Aboriginal health workers or sexual health workers appear to play a minimal role in providing HIV clinical services. Aboriginal health service models are based on comprehensive primary health care models. In reality, there is not the capacity to provide comprehensive care for all conditions, and there are well recognised barriers to the provision of HIV clinical care such as concerns about confidentiality and stigma and professional skill base (as with all low case load practices). Health workers have taken on the roles of support, liaison, education and prevention for sexual health matters: with HIV, their professional role is generally limited to these aspects and involvement with co-morbidities, rather than direct HIV clinical care.

The Australian workforce is distributed unevenly; which mirrors international trends. The ratio of health providers to population is much lower outside metropolitan areas. Non-urban professionals experience greater difficulties than their city colleagues in accessing training, support and relief. The health workforce is generally ageing, working fewer hours and becoming
feminised. In specialised areas such as HIV, a decrease in the numbers of younger trained doctors and nurses is noted. Training is in silos and there are too few training places. While there is a national trend, across nursing and medical sectors, for increased specialisation and a move from generalist medicine, complex, chronic conditions require a generalist health practitioner to provide coordinated and integrated care.

The strategies to respond to these health workforce deficits in Australia are relatively underdeveloped and generally untested. There have been some successes with financial incentives such as the Enhanced Primary Care program and the funding of practice nurses. Lifestyle incentives anecdotally have had success. System changes with support for multidisciplinary and shared care have shown some benefits as have mentoring and support (such as remote specialist networks).

Anecdotally, the many health professionals working in these areas of HIV medicine and with marginalised communities (rural and remote, Indigenous, CALD) remain there because of a personal commitment and passion. There is evidence that this situation will not continue indefinitely.

**Demonstration projects**

The Advisory Panel met three times over the course of the project, in April 2008 (at a preliminary one day workshop in anticipation of the contract development and signing), in September 2008 for one day and in early March 2009 for a 1½ day workshop. Prior to the final March meeting, all panel members were sent the background draft papers. The brief at that meeting was to provide comments, critiques and analysis on the background papers and to chart a course for the MACSD project to conclude its immediate work. The result was the unanimous recommendation that a series of demonstration projects should be undertaken to gather evidence and information and test hypotheses about aspects of HIV clinical service delivery and the future. The Advisory Panel considered that the proposed projects had fundamental strengths and resilience particularly against the background of the National (and jurisdictional) Chronic Disease Strategy and the HIV models that were being considered and implemented in different states and territories. These demonstration projects are also very important in a landscape where a current National HIV Strategy, National Primary Health Care Strategy or findings of the Preventative Health Taskforce were not available. The proposals build on work that is already underway in some cases (and therefore funded) or work that had been identified as requiring development.

The demonstration projects will be outlined briefly below. They have been presented to the Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmitted Infections (MACBBVS) and to BBVSS. Both groups gave in principle support to the proposals and agreed to work to implement them at jurisdictional and national levels. Appendix 2 has more detailed descriptions of the projects.

**Recommendations**

1. **Models for shared care**
   a. Implement a series of demonstration projects aimed at exploring mechanisms for facilitating and delivering shared care in the community. Potentially these will consider the role of specialists, S100 GP prescribers, non-S100 GPs, nurses
(nurse practitioners, practice nurses, specialist nurses) and other health professionals who are involved in delivery of different aspects of shared care: outreach, case management, integration with other specialties

b. Determine the features of community-provided shared care and who is referred for this level care:
   i. Level of patient need
   ii. Level of practitioner training required and delivery site(s)
   iii. Role, frequency and type of specialist review
   iv. Other contributors (community-based organisations)

   c. Develop a range of community provider supports
   d. Cost, document, analyse and communicate background information and results
   e. Explore strategies for sustainable funding
   f. Data collected from all enrollees and regularly contributed to, for example, AHOD/ARCSHS data sets.

2. High caseload S100 prescribers
   a. Develop and implement a series of tailored supportive solutions to support individual high caseload community practices to address workforce retention, recruitment, training and succession
   b. Cost, document, analyse and communicate background information and results
   c. Gather data and contribute to NCHSR/NHMRC project on barriers from this professional group
   d. Explore strategies for sustainable funding
   e. Data collected from all enrollees and regularly contributed to, for example, AHOD/ARCSHS data sets.

3. Nurse-based initiatives
   a. Explore, implement and evaluate a range of nurse based strategies aimed at increasing access to clinical service delivery
   b. These may include:
      i. Practice nursing
      ii. Nurse practitioners
      iii. Community based nurse models
      iv. HIV hospital nurses providing community/GP care
   c. Cost, document, analyse and communicate background information and results
   d. Explore strategies for sustainable funding
   e. Data collected from all enrollees and regularly contributed to, for example, AHOD/ARCSHS data sets.

4. Supporting and enabling recommendations
   a. Inclusion of the recommendations above as well as the enabling, supporting and additional priorities in the next National HIV Strategy
   b. The support of routine and longitudinal data sets such as ARCSHS
   c. The expansion of the AHOD data set
   d. Continuation of the joint BBVSS/MACASHH committee overseeing this project to act as implementation oversight group.

5. Other priorities
The activities included here were identified as being particularly important and were also thought to have been picked up by or incorporated in activities of third parties.

- Implementation of strategies aimed at increasing the linkage between laboratory and clinical settings
- Implementation of innovative strategies for linking with patients and with doctors at time of diagnosis
- Monitoring and promulgation of e-health strategies
- Monitoring, reviewing and revising initiatives to facilitate communication between services
- Monitoring, reviewing and revising self management strategies and exploring these in tandem with above priorities.

**Discussion**

**Methodology and evidence**

The information in this report has been drawn from many sources. The methods employed are reviews of national and international peer reviewed journal articles and reports from the internet, analysis of published national reports and surveys, interviews and questionnaires of key informants (policy and program officers, service providers and consumer representatives).

These data have provided a broad background to the project, so there is an amalgam of findings from recent international and national literature, supported by reports on the current Australian context about people with HIV, services for HIV and the HIV workforce. This is a comprehensive background to the problem of addressing the increasingly complex clinical care needs for the increasing number of people with HIV in Australia. The collected data, on which the analysis is based, are not, however, without limitations.

Australia is a socially and geographically diverse country, as are its residents with HIV. When considering the literature, it must be emphasised that there is very limited high quality evidence [Level 1 – systematic review of all randomised controlled trials (NHMRC 2000)]. Relatively few programs have been evaluated in Australia or overseas, and most of the evaluations focus on process or output and not outcomes (especially not health or clinical outcomes). The literature concentrates on evaluations of pilot studies, and the results of assessments of longer-term interventions (which would consider outcomes and sustainability of models and interventions of interest) are not available. The interventions that are studied and the endpoints that they are measured against vary considerably. Even when it seems that there may be common themes between programs, in our experience, it has been difficult to compare them and define effective practices. A related point when considering the international literature is its generalisability. Much of the work on HIV has been undertaken in resource-poor countries, or in marginalised groups in the USA. The underlying models of clinical service delivery, the supporting health system and political frameworks and the prevailing social, cultural and economic milieu are very different from those in Australia. Therefore, extrapolation of overseas models to Australia would have to be undertaken cautiously.

The surveys and interviews of key informants in Australia provide recent accounts of their understanding, attitudes, experiences and opinions. As much as possible, key informants were approached because they were considered to have a broad view and comprehensive
knowledge of the relevant issues. Largely, their contributions provided a qualitative snapshot of the issues. In the selection and interviewing of key informants, the project endeavoured to gather representative views (if the interviewee was representing a group or organisation). There is a risk that individual views will be presented instead.

The project experienced difficulties acquiring data in a very few areas. This was because of sensitivities (for example when mapping HIV populations against HIV services, the distribution of people diagnosed with HIV outside metropolitan areas was unavailable in some jurisdictions), time constraint, difficulties with process or absence of accessible information.

It is important to understand the strengths and limitations of methods used and the data extracted as they form the basis of our conclusions and recommendations for further research. In this paper and the earlier reports, we have aimed to be clear about the data at hand and the assumptions we have made.

Analysis: trends and gaps

We know that the number of people diagnosed with HIV in Australia is increasing, that they are living longer and that as a group they are getting older. Their HIV-related health concerns can be grouped into three stages: those who are well and not on treatment; those who are stable on treatment; and those whose therapy is complex and care services are multilayered. Additionally, health management is complicated by the side effects of treatment and the presence of chronic co-morbidities related to ageing and mental health deficits and needs. We know that people with HIV evaluate their health status as less than that of comparative non-HIV Australians (Grierson 2006).

The improvements in health brought about by advances in treatment have resulted in a move from specialist hospital-based inpatient services to specialist GP, sexual health clinic or hospital outpatient care. These services are concentrated in the inner urban areas of capital cities (and few regional centres). There are a number of service types available for those who reside outside the inner metropolitan areas. It is noted that access to antiretroviral prescriptions and dispensing centres is sometimes problematic. ARCSHS’s paper presented an analysis of three key sub-populations based on duration of infection from diagnosis (long-term positive and newly diagnosed) and stage at diagnosis (late presenters) (Carmen 2009). These categories were applied against the sub-populations’ service interactions and needs as well as social, cultural and economic patterns that modified service demands.

There remains variation between jurisdictions about sites and service types for people living with HIV to access their care and there are differences between key stakeholders as to who should deliver this care. In some jurisdictions, much care is provided by sexual health services (such as in Queensland), yet in other similarly large settings (Western Australia) there is a propensity to have care more centralised to specialist immunology or infectious diseases settings. In other states such as NSW, Victoria and the Australian Capital Territory there has been a greater reliance on HIV S100 prescribing GPs for the delivery of care.

The ARCSHS developed a hypothesis, that there are anticipated changes in service need related to changes in place of residence (Carmen 2009). This is based on the general Australian data and anecdotal reports from providers outside the inner urban centres. It has implications for developing the general level of infrastructure and providing training, supporting
health professionals to facilitate access and service delivery for older Australians with chronic conditions who are leaving the city, including those with HIV. That is, the response to people with HIV is a part of broader action, and the provision of HIV services should be built on the platform of integrated general health services. It also relates to the observation that the significant proportion of people who are stable on treatment require non-HIV clinical services and currently many rely on specialist services for generalist care. The need for non-HIV services (specialist medical and social) is anticipated to increase (e.g., mental health, cardiovascular, neurological, and housing) and benefit from the integration with HIV service providers. Qualitative and quantitative data on consumers, their movements, and service needs are required. There is a need to define the service models that consumers consider will best meet their needs now and in the future so that service providers can respond and integrate consumer preference, and the barriers and solutions required, into their projections, planning, and evaluations. They note the importance of defining the balance of specialist services and (integrated, coordinated) mainstream and other specialist services and systems to support their efficient operation. With the increase in the use of mainstream services by people with HIV for HIV care, guiding principles for services must include non-discrimination and equity of access. It is one thing to direct patients to mainstream services; it is another to have those services able and willing to service them. The importance of advocacy for health consumers, and the roles of carers, must be understood and supported across the system. Poor communication permeates and supports an inadequate health system. As well as improved management of health information, there must be a commitment to a culture of improved communication between all stakeholders — consumers, providers, funders.

There is an absence of data about the frequency or patterns of service use according to the stage of HIV: further data would assist in modelling service need over time for different sub-populations. None of the Australian work provides sufficient data on people living with HIV with complex health and service needs — to define what they are, what is available or could be delivered and what models would meet their needs.

Changes in the dominant paradigm of HIV care influence guideline development and standards of care delivery. There has been a repetitive trend for the paradigm to shift from earlier to later treatment commencement and then back again. Most recently, we are observing a swing back to earlier commencement of treatment as a strategy to preserve immune function. This practice has largely been brought about by the introduction of more manageable therapy which has a lower side effect profile, reduced toxicity and low pill burden. As care delivery moves away from a centralised HIV-specific core, the need to convey these treatment approaches increases. The frequency of these changes is a substantial factor contributing to calls for the greater centralisation to HIV assessment and the delivery of routine care through shared care arrangements.

So in all, we have substantial and largely representative information on Australia’s HIV populations over many domains: complete enough to generate many hypotheses (identify what we don’t know). Although based on the most comprehensive study available, the most marginalised (hospitalised with high needs, CALD, Indigenous, low health literacy and remote location) are under-represented (Grierson personal communication, 2009). It is an incomplete response, however, in defining many aspects of population and subpopulation service needs and projections for the future that will allow proper service and workforce planning.
implementation, coordination and integration and consequent improved clinical outcomes. Consideration of current services is the next step.

HIV clinical care is provided under a wide range of models in Australia. This variety is in response to the different underlying jurisdictional health systems, different state and regional HIV demography, competing health demands and prevailing HIV and generalist workforce situations. It is also a result of differential influence coming from practitioners with a particular perspective. All states and territories have publicly funded clinics that provide HIV clinical services. These may be stand-alone sexual health clinics, sexual health clinics as part of a public health or community health service, sexual health clinics as part of a hospital service or hospital outpatient services (sexual health, infectious diseases, immunology). All jurisdictions have hospital based HIV tertiary services – Centres of Excellence; with the change in the natural history of treated HIV, these centres have a reduced role in HIV management.

Most jurisdictions have S100 GP prescribers who work from private GP clinics, funded through Medicare (some bulkbilling) and patient out-of-pocket payments. In regional, rural and remote areas, service demand is variable and may not reflect the resident HIV population, who prefer to access HIV care from distant centres to safeguard their confidentiality. In theory, primary health care services in rural and remote areas are well placed to integrate HIV care as part of their chronic care work. There are many models employed to strengthen clinical service delivery and maximise the use of scarce and busy health professionals (Wakerman 2006). Aboriginal Medical Services (urban or regional) do not generally provide direct HIV clinical care or S100 prescribing.

The variety of models of HIV clinical service delivery is important when considering any proposed changes, for example integrating services or task shifting. These different services will have different abilities to respond to change. A general practice may extend its service range to provide more for people with HIV; a rural stand-alone sexual health service (based on a silo model) may be less able to integrate other services or provide multidisciplinary or team care (especially when there is 0.5 full time equivalent (FTE) nurses and 0.2 FTE visiting medical practitioners). Nationally, a number of services set up to respond to HIV (in sexual health and HIV units) are finding that they can no longer provide a general primary health service in addition to their sexual health or HIV service. A number of activities are being undertaken to encourage patients using these services into (or back into) the generalist health care setting. At the same time activities are underway in Western Australia and NSW to encourage general practitioners to continue to provide generalist services to their patients with HIV infection, while referring them on for specific HIV assessment and care.

The MACSD project has undertaken preliminary and incomplete mapping of the HIV population against HIV services. Only very broad comments can be made at this stage, as comprehensive population distribution data are unavailable. Firstly, the distribution of people with HIV and HIV services are broadly concentrated in similar areas. Secondly, rural and remote services have fewer FTE health professionals than their urban counterparts. However, there is a critical mass about locally based (as opposed to fly-in fly-out) staffing levels in sparsely populated areas; the consequence is that (specialist and generalist) country practitioners will be expected to provide clinical services across a range of areas as well as administrative responsibilities with minimal support. The third point echoes comments from the ARCSHS paper, that it is important to define anticipated population movement (from the city) to plan for future services. The ability of
rural and remote areas to provide comprehensive HIV care to an increasing population that is ageing with complex care needs will be challenging.

It was beyond the scope of this paper to investigate opportunities for mainstreaming aspects of HIV care in urban and regional areas. A further gap that will need to be considered in the future is the engagement of non-HIV specialist clinical services. If, as anticipated there are more cases of older people with HIV and chronic conditions associated with ageing and their HIV treatments, specialists (particularly cardiologists, neurologists, oncologists and geriatricians) will be faced with providing opinions and management for a range of problems complicated by HIV. There is no indication that these professionals or their health services have recognised the likelihood of this event.

Description and analysis of the HIV models of access and service delivery in Australia and internationally and review of approaches to service delivery for chronic diseases reveal many common approaches. The central themes are based on the Chronic Care Model (Wagner 1998) or its modifications. Overall, the HIV models are an unsatisfactory area to review because of the paucity of the data and the limited application to the Australian setting. In contrast, there is considerable evidence in chronic disease about various interventions and improved clinical outcomes, internationally and in Australia, that could be suitable to apply to HIV. Recent Commonwealth government activities such as the development of the Primary Health Care strategy and the Preventative Health Taskforce examine issues that will be of interest to all those in the HIV sector.

The Australian primary health care system is based on a general practice service model which is funded through a public-private mix. This model needs to be supported by an expansion of multidisciplinary teams that are patient-centred and integrated to provide comprehensive primary health care, particularly for complex (and chronic) conditions. This requires the reallocation of responsibilities so that service delivery mechanisms match the level of specialist and generalist care needed on a case-by-case or case-mix basis. Expanded models of Wagner’s Chronic Care Model better integrate prevention and health promotion activities (Barr 2003). These expanded models also require a consideration of a revision of funding to allow a wider range of non-medical (and non-nurse and nurse practitioner) service providers to be adequately remunerated for their roles under the Medicare Benefits Schedule (MBS), or alternative funding models to be applied such as capitation payments or funding for local service provision. Providers caring for those with chronic and complex conditions or social factors that impact on their health, and demand, for example, longer consultations, are directly disadvantaged by the system and are inadequately funded under MBS. Review of the funding structures is a high priority and HIV is an area where a pilot study may demonstrate useful findings that are generalisable to other areas.

The domains of the chronic care, HIV and primary health care models include the community, the health system (no fee for service or drugs, patient-centred, continuity and continuum of care, multidisciplinary, integrated, co-ordinated, supported by health information systems, evidence-based guidelines and quality improvement), communication between providers, communication between consumers and providers (both supported by adequate technology), an adequate workforce which is provided with support and professional training and development and an enabling political and financial environment. While the evidence is encouraging about the effects of many interventions at an individual service level, there is little
evaluation of chronic disease policy implementation at a broader level. Effective change across many services – or an entire jurisdiction – requires complex and staged interventions. One paper (Gillespie 2008) described the lack of integration of policy at the Commonwealth, state and territory and local levels as ‘...a set of horizontal discs with little overlap...’. The different priorities and assessments of problems and solutions at the various levels can result in tension, especially for those downstream, as well as isolation where the fundamental principles of models of service delivery may be viewed as empty rhetoric.

There is undoubtedly a challenge in testing and applying new or modified models of access and service delivery for HIV in Australia in the current atmosphere of global financial uncertainty and health system review and revision. The literature argues compellingly that not to address the changes to our nation’s health status and re-position and focus our health system and services to prevent and respond to the increasing demands from chronic illness and complex conditions is short sighted, irresponsible and a profligate waste of community resources.

As Michael Saag points out (Kaiser Foundation 2006):

> But I have to say that, what good are medications if there are no providers to provide care? This is tough business. This is hard to do well. It is easy to mess up. You need educated, well-versed practitioners seeing these patients and if they aren’t there the medications are just going to be misused and we are going to have a health care crisis of resistant virus like you can’t imagine.”

> and

> “Without drugs providing care is difficult to impossible, true, but add to that without qualified care providers in clinics, HIV drugs mean nothing and that is a fact...”

In Australia, the health workforce is undersupplied across the fields of nursing, medicine and Aboriginal health workers. This shortage is magnified outside inner suburban areas where the population/practitioner ratios are much higher. The health workforce is generally ageing, increasingly feminised and tending to work fewer hours. Both nurse and doctors are becoming more specialised, with comparatively fewer GPs and generalist nurses practising. Generally, there are problems in training adequate numbers of nursing and medical undergraduates, either because of too few university places (although an increase in medical graduates is expected in the next few years as a result of increased funding and expansion of available university places), or recruitment and retention difficulties.

Professional bodies for doctors, nurses and Aboriginal health workers set out different standards across the country. Nurses have national accreditation bodies and doctors have national professional colleges, but registration is a state or territory based process. National recognition of further training is not automatic. The overall picture is one of health professionals regulated by a raft of professional bodies across each jurisdiction. The result is minimal overall planning and co-ordination and limited ability to identify and respond flexibly.

Attracting and retaining graduate doctors and nurses to the areas of HIV medicine or sexual health results in an escalation of the already unsatisfactory situation. These specialities are not particularly popular, nor sufficiently popular to meet demand, post graduate training opportunities are limited, the support and mentoring given to practitioners is frequently patchy, recognition of their increasingly complex professional responsibilities is limited and financial
rewards are not generally regarded as satisfactory. Professional education is frequently driven by demand. As this is uneven or limited outside metropolitan areas, the lack of opportunity for updating or consolidating skills outside Sydney or Melbourne is compounded.

There is limited evidence in Australia of effective and sustainable interventions to recruit, retain and train medical, nursing and health worker staff generally or in the areas of HIV or similar chronic conditions that can be managed at primary and secondary health care levels. The recruitment of overseas trained doctors has been one strategy which has delivered benefits especially to rural and remote Australia, but there are real concerns about the level of professional and personal support and guidance these practitioners are given when they step into some of the least sought after medical jobs in the country. The capacity of overseas trained doctors to provide complex HIV care has not been assessed. The professional colleges and bodies who have the responsibility of making recommendations to government about the need for undergraduate and postgraduate training have not generally demonstrated an awareness of the evolving changes to the HIV population and the impact of these changes on HIV service delivery, workforce capacity and consequent workforce demands.

Education and training of professionals cannot be restricted to clinical aspects. If other models of service delivery are implemented, provider capacity must be developed and these providers must be supported to engage with new models and revised professional roles. The responses will need to be multtiered, considering the underlying health system in a particular jurisdiction, the distribution of people with HIV and their service needs and preferences, the distribution of interested generalist and specialist health providers, the opportunities for task shifting, the capacity to introduce or strengthen chronic care models and the reality of services facing high staff turnovers and recruitment difficulties. The issues facing high case load HIV GPs have already been raised in demonstration model 2: these relate to ageing, work-life balance, inadequate remuneration and recognition and professional burnout.

It appears that to comprehensively address Australia’s health workforce problems (and therefore address HIV workforce issues) will require a grand plan and cooperation across all levels of government and the private sector. This is unlikely in the short term, so we are left with considering what has been effective and applying that or testing models that have shown some promise.

**Demonstration projects**

The demonstration projects have been selected and developed because they reflect current and anticipated state, territory and Commonwealth strategic directions, both HIV, primary health care, preventative health and chronic disease. They are supported by enabling projects that are fundamental to the understanding of many areas of HIV including clinical service delivery that will come out of the National HIV priority areas. The proposed work by ARCSHCS was selected and prioritised because it builds on previous methodology and findings additionally it will look more closely at patterns of service use (driven by access, availability, demand, need and preference) which will inform service planning. The expanded AHOD aims to examine clinical outcomes related to service use and increase the coverage to represent the full spectrum of people living with HIV.

Investigation of the applicability and effectiveness of models of shared care in the HIV area will define, develop and assess both practices that are already underway and potential areas for
shared care. S100 prescribing GPs will be the core of this project. The opportunities to share the care of patients with HIV with a team of (HIV) specialists, non-HIV GPs and nurses (practitioners, practice nurses, HIV nurses) will be considered and the methods of implementing this will be defined. Data about community based (primary health care) and client features will be collected. Barriers and risks will also be assessed and responded to and community provider supports developed and provided. The ARCSHS and AHOD data will inform this project. Community provider supports will be flexible and responsive to provider need. GPs are at the core of Australia’s health delivery, changes must be consultative and inclusive with appropriate financial incentive.

General practice is at the centre of our primary health care system. High case load GPs provide the majority of care for people with HIV (56%) (Grierson 2006). Problems of provider ageing, inadequate support and financial reward, the low likelihood of recruiting younger or new GPs to replace older practitioners have been identified as reasons for the attrition and projected attrition of the backbone of HIV clinical service. This project will explore these issues (and others) and develop and test interventions to address high case load workforce issues. This project will coordinate with the NHMRC and NCHSR project examining high case load GPs satisfaction and barriers. It is a key area to focus on, because of the role of these GPs and the impact of their movement from the sector (without replacement). The project draws on key elements of the National HIV Strategy, areas discussed in the Primary Health Care Strategy background paper and the National Chronic Diseases Strategy and the MACSD project workforce background paper.

Like high case load GPs, nurses are a fundamental part of access to and delivery of HIV clinical services. The demands of health workforce undersupply require a review of service roles, role expansion and task substitution. The literature supports expanded roles for nurses in the chronic disease field which can be applied to HIV. It is timely to consider the nurse practitioners, specialist nurses and practice nurses and their collaboration with medical providers. Much is made of the reluctance of doctors to relinquish any aspects of patient care. This aspect will need to be carefully defined and responded to in the HIV sector. Already many nurses work in semi-independent roles within the HIV sector, as research nurses and nurse practitioners in clinics. To date medical practitioners in HIV have been willing partners in teamwork with nurses. Increasingly there will need to be the exploration and development of service provision models which maximise the available workforce and strategies to leverage the best outcomes as much as possible within available resources. In the HIV setting, this may be the expanded and different roles of nurses in the community setting and shared care between, specialists, generalists and nurses. Such changes are becoming well established in the hepatitis C sector, despite the initial reservations of clinicians and managers. Each of these models will need to be employed across the sector in order to meet service needs into the future.

The other demonstration projects are equally strategic. Examination of issues around the time of diagnosis for the patient and diagnosing clinician sets the scene for high quality clinical care, provides clinician education and support, provides patient education and support and establishes the environment for early (preventative) interventions and models such as self management. This area has been identified as one that has not been well done in the past. Responses are already partially underway in NSW, Western Australia and Victoria, with Queensland interested. Each of these models is in development with different features, responding to different priority areas. It will be important to provide forums for the exchange of
experiences and the sharing of findings in relation to the implementation and evaluation of these models.

Efficient, user-friendly health information systems are fundamental to high quality professional communication, clinical management, data extraction and management. E-health systems have been on the agenda nationally and in many jurisdictions although there has been little progress because of the perceived scale of the project. Health information systems are part of the supporting and enabling environment for the delivery of chronic care models. Queensland Health is developing a tool for clinicians and a platform that will allow public health and private practitioners to communicate effectively and confidentially. The development, implementation and evaluation of this work will be of great interest and extremely useful to the rest of the country. Central Sydney Sexual Health Service is about to pilot an electronic health record in sexual health and is in the process of refining the data which will be collected and recorded to support it.

All the demonstration projects draw on findings from this project related to gaps in qualitative and quantitative data on HIV populations and HIV services, on the potential of particular models of access and service delivery and on the need to respond to the very problematic state of the general and HIV health workforce.

Change can occur on many levels. The literature and national and international strategies and frameworks present the importance of macro-, meso- and micro-reform. It is not feasible that this project will generate a major overhaul of national and jurisdictional health service delivery to result in coordinated, collaborative and integrated services, although without advances at the macro- and meso-reform level, progress will be jeopardised. To maximise results and efficiencies, the project has attempted to recognise and work with changes at the state, territory and Commonwealth levels.

The MACBBVS and BBVSS will need to consider capacity to resource these initiatives in the context of ongoing budget planning and the development of the new National HIV Strategy.

This project has collected and analysed key areas to Australia’s response to the increasing complexities of HIV care. It is a comprehensive piece of work which has provided not definitive answers but a solid platform for ongoing projects to inform change. The Advisory Group recommends that it continue as a subcommittee of MACBBVS and BBVSS to oversee the implementation of these demonstration projects and future work that will arise. There is strong support for this from both committees and a deep appreciation of the need to continue the momentum established by this project and benefit from it.
References


McNally S, Dutertre S. Access to HIV prevention information among selected culturally and linguistically diverse (CALD) communities in Victoria. Australian Research Centre is Sex, Health and Society, Latrobe University, Melbourne, 2006.


Appendix 1

The Models of Access and Clinical Service Delivery Advisory Group

The Advisory Group is chaired by a representative of NCHECR. It will have representation from HASTI, BBVSS and HIV clinical experts. The project activities will guide the activities of this Advisory Group. In addition, the Advisory Group will provide direction for discussion papers.

Jonathan Anderson  Chair; NCHECR, GP Melbourne VIC, President ASHM
Gary Boddy  BBVSS QLD
Lisa Bastian  BBVSS WA
Vicki Sinnott  BBVSS VIC
Robert Mitchell  HASTI, President NAPWA
Sharon Lewin  HASTI, Alfred Hospital VIC
Andrew Grulich  HASTI, NCHECR
Bill Whittaker  NAPWA
Jo Watson  NAPWA
Jason Appleby  AFAO
Trish Langdon  AFAO
Marlene Velecky  NSW Health
Levinia Crooks  ASHM
Clare Willington  HASTI, GP Canberra ACT
Mark Bloch  GP Sydney NSW
Cathy Pell  Sexual Health Physician, Darwin NT
Penny Kenchington  Sexual Health Nurse, Townsville QLD

Observers:
Nick Parker  DoHA (March 2009)

Project Steering Committee
ASHM  - Levinia Crooks
NAPWA  - Peter Canavan
         - Jo Watson
Project officers  - Stephanie McLean (ASHM)
                  - Jan Savage (ASHM)
                  - Marina Carman (ACRSHS)
Models of Access and Clinical Service Delivery Advisory Group activities (terms of reference)

1. Review the current models of HIV clinical service delivery to determine if they meet the needs and health care demands of people with HIV. This review will be in the context of the complex and diverse nature of HIV/AIDS care and increasing HIV caseloads, particularly in relation to issues identified in the Report of the HIV Clinical Complexities Forum – Health System Issues and Challenges in Complex HIV Care (November 2006).

2. Map existing HIV clinical services, general practitioners, Section 100 prescribers and HIV positive populations. Provide an analysis of these data including gaps in the information available.

3. In consultation with people infected with and affected by HIV, and health services providers, identify effective models of HIV clinical service delivery operating in Australia and overseas which could have wider applicability in delivering HIV/AIDS clinical care in Australia.

4. Identify any aspects of Australian and overseas models of clinical service delivery in other chronic disease areas which could enhance the delivery of HIV/AIDS clinical care in Australia.

5. Provide advice for the improvement of current care models to inform policy, research and service delivery. This advice will be provided to Commonwealth and State and Territory governments (through the BBVSS) as well as the community sector through ASHM’s website.

6. Review skills, experience and training needs for advanced, intermediate and basic HIV care, including the use of antiretrovirals and medicines for HIV related conditions, in relation to future models of access and clinical service delivery.

7. Following the development of the new models of access and clinical service delivery, review the workforce capacity to project the future needs of hospital, sexual health clinic and general practice based HIV care. Refer to the Report of the HIV Clinical Complexities Forum – Health System Issues and Challenges in Complex HIV Care (November 2006) and findings of the discussion papers produced as part of this project.

8. Provide a detailed workplan for this project including high level budget expenditure and work allocations.

9. Provide the Commonwealth, a minimum of three (3) and up to six (6) discussion papers that outline principles, standards, data analysis and evidence on the effectiveness of the current and future HIV models of care, access and clinical service delivery, including capacity, deficiencies and adaptability to the changing nature of HIV.
Principles for Models of Access and Clinical Service Delivery

At the Advisory Group’s meeting of the 5-6\textsuperscript{th} March 2009, the following principles were endorsed.

1. Services
   a. General principles to guide:
      Patient centred, holistic, comprehensive, multidisciplinary teams, coordinated, flexible, planned, evidence based and supported
   b. Community-based services
      Recognise and support complementary and distinct role of community-based services
   c. Non-clinical services
      Recognise and support role of non-health issues in determining health outcomes, eg. housing
   d. Provision of spectrum of responses from prevention to end-of-life (continuum) as well as continuity of care.

2. Clinical information systems:
   a. Evidence-based guidelines, health plans, recall, reminder and follow-up systems

3. Delivery systems
   a. Self management, shared care, nurse practitioners, supported or comprehensive care, hub and spoke, fly in fly out, telemedicine, referral pathways and access to primary and specialist and multidisciplinary health care, hospitalisation, rehabilitation, palliation and end-of-life care
   b. Access issues
      i. Location, physical access
      ii. Cost
      iii. Hours of service
      iv. Perception of quality
      v. Sociocultural
   c. Workforce
      i. Support workforce development and strengthen workforce to support and manage change
      ii. Recruitment, retention, training and succession management

4. Information management
   Recognise and support roles of information management and communication technology

5. Support research, evaluation, monitoring

6. Recognise and support need for Centres of Excellence (including obstetric, paediatric and refugee)

7. Horizontal and vertical equity
Appendix 2  Mapping of HIV services
Appendix 3

Demonstration projects

The following projects were developed at the final meeting of the Models of Access and Clinical Service Delivery Advisory Group on 5-6th March 2009. They were prioritised and presented with further recommendations to MACASHH and BBVSS.

1. Models for GP or alternative clinics and services
   - GP and state services
   - Physical support (e.g., buildings)
   - Remote access (public health physicians access to Medicare)
   - Level 5 Medicare – billable specialist hours

   This model was redefined as Clinical Nurse Consultant (CNC) from hospital or a nurse practitioner (NP) to provide outreach in GP clinics (option 1 below)
   a. Description
      i. Option 1 CNC/NP outreach into GP clinics
         1. Shared care planning
         2. Secondary consults
         3. Case review
      ii. Option 2 CNC/NP employed in high case load GP clinic (dealt with by demonstration 2)
      iii. Option 3
         1. Clinical placements for GPs and practice nurses in hospitals
         2. GPs probably require funding through Medicare Benefits Schedule (MBS)
         3. Incorporate into RACGP learning program (active learning module) and the Royal Australian College of Nursing (RACN). Education delivered through ASHM, Australian General Practice Network (AGPN) (Commonwealth funded).
      iv. Option 4
         1. Outpatient clinics provided in communities funded through MBS

   b. Lead agency: State hospitals
   c. Support agency:
      i. GP clinics
      ii. Divisions of General Practice
      iii. Training bodies: ASHM, UQ
   d. Location: within GP clinics
   e. Partners: funding bodies, support agencies
   f. Target groups:
      i. High caseload GPs
      ii. Perhaps medium caseload GPs
   g. Evidence base:
      i. WA outreach service
      ii. Data on inappropriate presentations to hospitals (NSW, VIC HARP, QLD models of care)
   h. Evaluation strategy:
      i. Documented care plans (output)
      ii. Activity (process)
      iii. Stakeholder satisfaction – patient, GP, CNC (outcome)
iv. Patient quality of life (outcome)

v. Cost-benefit analysis
   1. cost savings of nurse undertaking GP tasks (Commonwealth)
   2. decrease in inappropriate admissions to hospital (states and territories)
   3. evaluate efficiency dividends of more patients and higher quality service

i. Timeline:
   i. 18 months set-up and evaluation
   ii. 12 months of project implementation

j. Funding/resourcing
   i. Large tertiary hospitals may be able to provide CNC for outreach consultation as part of their service, otherwise would need funding for nurse to hospital. The effective fulltime staff requirements would depend on number of practices supported
   ii. Noted that public health (VIC) funds something similar now.
2. **Mechanisms to access nursing and other support.**

   a. **Description:**
      i. Define and evaluate nursing professionals contributions to HIV practice in a variety of settings
      ii. **Descriptive: data collection and questionnaire based**
          1. GPs, specialists, nurses, clients
          2. Nurse roles
          3. Benefit to practice
          4. Benefit to clients
      iii. **Cost benefit analysis/Cost effectiveness analysis**
      iv. Develop business case for nurses

   b. **Lead agency:** ARCSHS, NCHECR (?NCHSR)

   c. **Support agencies:** S&T, GP divisions, ASHHNA, APNA, ANF, DoHA

   d. **Location:** national

   e. **Partners:** NAPWA, QPP, Positive Life (and support agencies) and others

   f. **Target group:** within HIV sector wherever nurses are employed

   g. **Evidence base:**
      i. Practice nurses – care plans for chronic disease, obstetrics, child health
      ii. Advanced practice nurses – Sydney sexual health centre
      iii. Nurse practitioners – Melbourne, Townsville, Canberra sexual health centres

   h. **Evaluation strategies**
      i. Qualitative questionnaires – description of service satisfaction from GPs, nurses, clients, specialists (process)
      ii. Link to current strategies

   i. **Timeline:** 12 months

   j. **Other issues:**
      i. possible cost benefit to services by using nurses and freeing doctors time, fewer specialist consults (substitution)
      ii. opportunities to piggy back on or use existing models of nursing service initiatives.
      iii. there are other areas in the Commonwealth that may provide opportunities.
3. **Shared care**

a. Description
   i. follow-up script – with training
   ii. Nurse practitioner – outer Sydney, North Coast, Central Coast, Blue Mountains
   iii. Sexual health centre – referral
   iv. Mentoring – AIDS Medical Unit
   v. Who coordinates the care? Issues about managing a chronic condition with GP, nurse, NP; funding and remuneration possibly through Medicare item numbers; suitable and available services.

b. Location - treating GP and practice nurse, phone line, outreach

c. Funding – to GP, ?specialist, paid – care plan, funding for education, delivery of module and ongoing follow-up support

d. Target groups
   i. GPs with interest in provision of basic HIV care (not full Section 100)
   ii. In formal partnerships with HIV specialists
   iii. Urban, rural and regional settings

e. Evidence base
   i. Area * data need regional data with an area coordinator and a link to AHOD (funded)
   ii. People by postcode

f. Training/support
   i. 3 hour module in house
   ii. Designated website
   iii. Annual review of prescribing rights (problem)

g. Timeline - link to current

h. How identified
   i. Divisions
   ii. Current prescribers
   iii. People with HIV
   iv. Area coordinators
   v. Advertising promotion
   vi. Infectious diseases physicians

i. Role
   i. Blood tests, viral load, CD4
   ii. Continuation scripts
   iii. Dispensing
   iv. Monitoring treatment
   v. Coordinating care – care plans

j. Other- not just targeted prevention program, across DOHA, there are 14 portfolio outcome areas linked across departmental outcomes

k. Timelines link to current
4. **Time of Diagnosis Pilot (patient and clinician):**

This is funded and ready to implement in Western Australia.

a. **Description:** Throughout Australia, about 50% of new HIV diagnoses are made by GPs who have never or rarely made an HIV diagnosis.
   i. This project aims for GPs to be contacted immediately after making an HIV diagnosis with an information pack for both doctor and patient. This would lead to capture of information re: the GP and any ongoing training requirements that arise. Additional data may emerge (eg circumstances of how diagnosis was made).
   ii. The patient will receive information, referrals and a pathway for support services
   iii. To develop online patient-focused algorithms for the patient journey for use by patients and clinicians, eg through integrated check list – drop down boxes.

b. **Lead agencies:** ASHM, WA Divisions of GP, Curtin (evaluation partner), Public Health Unit at Geraldton.

c. **Location:** WA (statewide) (QLD may buy in for enhancement)

d. **Partners:** GPs who are experienced in diagnosis and can provide peer based and collegiate support and advice to project (may include participation in future training as well) (Also consumer groups??)

e. **Target groups:**
   i. GPs who rarely diagnose HIV
   ii. Newly diagnosed people with HIV

f. **Evidence base:**
   i. Effectiveness of early intervention on life course outcomes
   ii. Impact of poorly delivered diagnosis and long term impact
   iii. ?GP evidence on confidence/information requirements when delivering new diagnoses (compared with other serious conditions eg cancer)

g. **Evaluation strategy:**
   i. GP satisfaction, ease of use, confidence in use
   ii. People with HIV satisfaction
   iii. 6 month (?) follow-up. What did you from project? What did you use? What was helpful, what wasn’t?

h. **Timeline:** 2 years

i. **Other issues:** work in GP, community sector and people with HIV
5. **AHOD and ARCSHS**

   a. Description: development of a collaborative longitudinal study looking at clinical outcomes, service preferences and model preferences.
      i. Examining occasions of service repeated measures study – to track changes in patterns of service use over time to characterise intermittent and regular low level service demand,
      ii. Examining retrospective service use history analysis to characterise patterns of service use and the relationship of this to clinical and social histories and to identify social and structural barriers to service use.
      iii. Encompassing a range of clinical and non-clinical and non-health services.
      iv. Tracking and defining trends.
   b. Lead agency: ARCSHS
   c. Support agency: collaboration with AHOD (NCHECR and partners)
   d. Location: National
   e. Partners:
      i. Research bodies
      ii. Community
      iii. Clinics and care providers (clinical, social, non medical etc)
   f. Timeline: Maybe minimum of 2 years

This continuing work is regarded as fundamental research relevant to many areas of HIV. Concerns were expressed about the disconnect between research and evidence-based practice since last strategy.
6. **Electronic health records**

   a. Description: Evaluation of the Queensland Health Population Health Information and Clinical Services Solution (in development). Queensland is developing an electronic system based in sexual health (also now including TB, family planning and linking with GPs and Aboriginal Health Services). Patient gives permission to link to GP evidence base. Currently at very preliminary stage
   
   b. Lead agency: Queensland Health – division of sexual health
   
   c. Support agency: GPs, Family Planning, Aboriginal Health Services
   
   d. Location: QLD
   
   e. Evaluation strategy:
      i. Qualitative evaluation of development process
      ii. Clinical outcome measures over time
      iii. Client satisfaction, at baseline and follow-up
      iv. IT issues: how sustainable is such a system?
   
   f. Timeline: dependent on timeframe of project implementation
      i. Phase 1: start with baseline over next 12 months
      ii. Phase 2: clinical outcomes and service utilisation
   
   g. Other related issues:
      i. Rollout of other IT systems for chronic disease in primary care
      ii. SA
      iii. WA telehealth
      iv. Pilots in NSW in HIV and STI
      v. Lots of risks with IT and timeframe (nationally, attempts to get systems up for a long time)
      vi. Application to research and program evaluation and monitoring as well as clinical management
      vii. QLD acknowledges importance of confidentiality and client control issues and is trying to manage these.
7. **High HIV case load S100 prescriber project**

a. Description: High case load GPs encounter difficulties in providing clinical services. The domains may be described as systemic: time, frequency, complexity (e.g., medicare and clinical management), training, policy, and partners (e.g., dispensing regulations and referral pathways) and consumer driven (e.g., adherence). The project aims to investigate these issues and their impact on models of service delivery, practitioner recruitment and retention (and succession) and recommend solutions.

b. Lead agencies: ASHM, NCHSR

c. Support agencies: RACGP, AGPN (Divisions), Highly Specialised Drugs Working Party

d. Partners: NCHSR, NCHECR, Primary Health Care strategy Working Group

e. Target groups: High case load S100 prescribers, low case load and no case load (for shared care)

f. Evidence base:
   i. Kristie Newman (NCHSR)
   ii. Chronic disease and medicare item numbers (e.g., enhanced primary care)
   iii. Productivity commission workforce
   iv. Caseload issues (Jeffrey Grierson ARCSHS)
   v. ARV guidelines and checklist

g. Evaluation strategy:
   i. Output: report and recommendations with identification of barriers
   ii. Process: sample size, comparative groups
   iii. Timeline: 12 months

h. Funding: Commonwealth (national project/data)

i. Other issues: fits well with other models – provides risk assessment for other aspects
8. Early intervention linked to Time of Diagnosis

a. Description: Self management with as referral process to address progression to co-morbidities. Completion of lifestyle questionnaires by patient (12 monthly); clinician tests for clinical markers (renal, lipids, bone density, STI, TB, vaccination), patients attends relevant services; clinician refers to services; resources/info lead to patient questions; patients handouts provided by doctor for social supports, nutrition, smoking case management etc.

b. Lead agencies: To be finalised, possibly NAPWA and AFAO, with Commonwealth, state and territory participation

c. Support agencies:
   i. high case load GPs (Mark Bloch mentioned)
   ii. AHOD

d. Location:
   i. Multisite? Regional, inner city, Sydney and ???

e. Partners:
   i. AHOD for clinical markers
   ii. Positive Life, NAPWA

f. Target groups: Positive people, diverse

g. Evidence base:
   i. chronic disease self management (pre and post study survey)
   ii. models in many chronic disease fields
   iii. Immunisation Blue Book
   iv. NAPWA resource

h. Evaluation strategy (not of problems identified, but of intervention):
   i. Lifestyle modification markers
   ii. Provider/consumer satisfaction
   iii. Clinical outcomes

i. Timeline:
   i. 2-3 years for co-morbidities
   ii. 12 months for lifestyle satisfaction

j. Other issues: Interest in WA where most services delivered through hospital clinics, not GPs (with preventative primary health care focus and experience with early interventions)
Priorities

- Models of shared care (Projects 1 and 3)
- Workforce issues: High case load GPs (Projects 2, 3 and 7)
- Models for development of nursing roles (Projects 2 and 3)

Underpinned by Project 5 – ongoing longitudinal data on HIV populations, service use and clinical outcomes is fundamental. ARCSHS and AHOD (and NCHECR and NCHSR)

What is already under way?

- Time of diagnosis (4) (focusing on clinician) need to add Early intervention to support patients (8)
- Electronic health records (6)

These priorities fit with the priorities of the current national strategy and need to be carried forward in the 6th National Strategy. The links, implications and potential for other strategies to dovetail (eg NPHCS, NCDS and preventative taskforce work) need to be identified and developed.

Gary Boddy proposed that this Advisory Group become a working group of MACBBVS; additionally it was noted that there are linkages to both the Commonwealth and the jurisdictions, and that therefore the Group should be a working group of both MACBBVS and BBVSS.

Bill Whittaker proposed that the states and territories are asked to provide information about their reviewed, revised, new strategies and the project priorities. Gary Boddy agreed to this on behalf of BBVSS.

It was agreed that the minutes from this meeting will be forwarded to the Commonwealth.

Recommendations:

- All demonstration projects were recommended and prioritised.
- That this Advisory Group should be a working group of both MACBBVS and BBVSS.
Appendix 4

Levels of chronic and complex care management

Level 1
People with chronic diseases and complex needs who frequently use hospitals and are assessed as meeting the HARP CDM screen

Level 2
People with chronic diseases and complex needs who use hospitals or are at risk of hospitalization and are assessed as meeting the HARP CDM screen

Level 3
People with chronic diseases and/or complex needs

Level 4
Whole population

Intensive care coordination
- Care across the continuum
- Tertiary and secondary prevention
- Enrolled patient population
- Comprehensive assessment and care planning
- Specialist medical and GP management
- 24 hour advice
- Additional services where appropriate
- Self-management approach
- Comprehensive hospital discharge planning

Primary Prevention
- For example: obesity reduction, smoking cessation

The Chronic Care Model

### Appendix 5

#### Distribution List

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<tr>
<td>Observers at MACSD Advisory Panel meeting 6th and 6th March 2009</td>
<td></td>
</tr>
<tr>
<td>Members of BBVSS (Commonwealth (DoHA, OATSIH), state and territory health bureaucrats, AFAO, NAPWA, ASHM, AIVL)</td>
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<td>NSW Health (CNC)</td>
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<td>Michael Doyle</td>
<td>Aboriginal and Rural Health Curtin University WA</td>
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<td>Stephen Duckett</td>
<td>Queensland Health (public health)</td>
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<td>Tom Gottlieb</td>
<td>President elect Australasian Society for Infectious Disease</td>
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<td>Bronwyn Harvey</td>
<td>Commonwealth DoHA</td>
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<tr>
<td>Kay Hull</td>
<td>Federal MHR, Member for Riverina</td>
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<td>Michael Kidd</td>
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<td>Lewis Marshall</td>
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<td>Robert Monahan</td>
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<td>Chair, Preventative Health Taskforce</td>
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<td>Christy Newman</td>
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<td>Donna Tilley</td>
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<td>Kate Ward</td>
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<tr>
<td>Rosemarie Winsor</td>
<td>WA Practice Nurse (WAPNA member)</td>
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