

Models of access and clinical service delivery for HIV positive people in Australia: managing complex and stigmatising conditions outside urban Australia

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Background to project

In Australia, the number of people with HIV is continuing to increase, and those with HIV are living longer. The Models of Access and Clinical Service Delivery for HIV positive people in Australia (MASCD) project was in response to:

- the clinical course of HIV in becoming a treatable chronic condition
- increasingly complex treatment
- more complicated clinical management due to age-related problems and co-morbidities of increasing frequency and severity (e.g. cardiovascular, mental health, neurological, oncologic)
- the psychosocial environment of people living with HIV as they age, access and treatment issues for people from culturally and linguistically diverse groups and Aboriginal people
- and workforce shortages as ageing health professionals retire, particularly in rural and remote areas.

This project is funded by the Commonwealth, States and Territories (steered through the Blood Borne Viruses Sexual Health Sub Committee (BBVSS) who in turn commissioned the National Association of People Living with HIV/AIDS (NAPWA) and the Australasian Society for HIV Medicine (ASHM) to investigate these critical areas. An Advisory Panel has been meeting regularly to provide guidance and direction to this work, and has recently endorsed a number of demonstration projects which capture the key priorities and are supported by the current 5th National HIV/AIDS Strategy. These are to be presented to the Commonwealth Ministerial Advisory Committee on Blood Borne viruses (MACBBV) and BBVSS.

A number of papers have been written to analyse and develop these issues. Key areas are summarised here as they relate to the management of complex and stigmatising conditions outside of urban Australia. The final report summarises service access and delivery issues and workforce implications and presents the rationale for the demonstration projects.

Demographics

Approximately one-third of Australians live outside Major cities. People living in rural areas tend to have shorter lives and higher levels of illness and disease risk factors than those in major cities. It is also true that, on average, people living in rural Australia do not always have the same opportunities for good health as those living in major cities. For example, residents of more inaccessible areas of Australia are generally disadvantaged in their access to services, education and employment opportunities and income (AIHW, 2008).

At the end of 2007, the estimated number of people living with HIV (PLHIV) in Australia was 16,692. While the rate of new HIV infections was declining prior to 1999, it has increased each year since then, predominantly amongst men who have sex with (ARCSHS, 2009). Important emerging questions raised here relate to how the ageing of the HIV-positive population, and other economic and social trends, are influencing the location of the population, and therefore service demands. (ARCSHS, 2009)

Geographic location

Some differences are emerging between states and territories, with NSW having a relatively stable rate of new HIV infections between 2003-2007, while other states recorded increases, particularly Queensland and Victoria (NCHECR, 2008: 7). In HIV Futures 5, the state/territory location of respondents was collected, along with 'area type'—capital city/inner suburban, outer suburban, regional centre, and rural. The majority of HIV positive people in Australia live in capital cities and inner suburban areas (ARCSHS, 2009).

The centralised location of populations of gay and homosexually-active men (particularly in Sydney) has assisted in service access and delivery. However, there has been an increasing focus in the HIV sector on service delivery for those living in rural/regional areas, and for populations which are more geographically dispersed—e.g. Aboriginal and Torres Strait Islander (ATSI) people, culturally and linguistically diverse populations, and positive heterosexual men and women. ATSI people in particular are more likely to live in non-metropolitan areas; 54% live in rural or remote areas, compared with 20% of the Australian population in general (ARCSHS, 2009).

Service use by people with HIV

Across all area types, those in the outer suburbs were the least likely to visit an HIV GP/s100 prescriber for HIV-related medical care (27% compared with 52% for those residing in inner suburban areas). People in outer suburban, regional and rural areas were also more likely than those in the capital city/inner suburban areas to access specialist HIV care at a sexual health clinic. People from the outer suburbs were more likely to have visited a HIV specialist at an outpatient clinic (47%) than a HIV GP/s100 prescriber (40%) (ARCSHS, 2009).

Those living in outer suburban areas were the least likely to see their HIV GP or s100 provider for general medical treatment (29% compared to 34% for those in rural areas). People in outer suburbs, regional centres and rural areas were more likely than those in inner suburban areas to receive general medical care at sexual health centres. These differences may be related to geographic accessibility of HIV GPs and specialists. However, it is also possible that people living with HIV in rural areas prefer to travel to regional centres or cities for all their medical treatment rather than see the local GP. This may be for reasons of confidentiality and/or to ensure quality of care (ARCSHS, 2009).

Theory to support models of access and care

The following theories have been used to understand and further develop models of access and service delivery for HIV positive people in Australia.

Chronic care model

Throughout the literature there is agreement that our health systems and services have developed in response to acute medical conditions. In reviewing jurisdictional, national and international responses to the clinical management of chronic diseases—or rather, the management of people with chronic disease, recurring themes emerged. These include models that are patient centred where the patient, their carers and “significant others” must be well informed and “empowered” to have an active role in their health care (AIHW, 2006). The system must be multidisciplinary, composed of different levels of care and care providers for different stages of disease. High levels of communication and different modes of communication between providers and consumers are essential; this includes systems that are supported by sophisticated, efficient and effective information management infrastructure. The delivery of the models of care must be planned, well coordinated, and they must be integrated into existing (and new) systems (WHO, 2006). Workforce issues are a central theme that is fundamental to the success of these models. Appropriate recruitment, training and support of workers is mandatory; a range of strategies (including incentives) addressing the problems inherent in maintaining an appropriate full and trained workforce must be developed.

International approaches to access and clinical service delivery

There is little evidence in the international literature on the effect of various models of HIV service access and delivery and clinical outcomes. However, there is some evidence, outside Australia, that the following factors may make a difference (Hanford; Tynan, Rackal 2006; British HIV Association 2007; Canadian Public Health Association 2006):

- multidisciplinary and multi-faceted services
- the presence of health information systems
- out-of-hours services (evening and weekend)
- free clinical services, free ART
- distance to services
- perceived quality of care and availability of therapy
- waiting times (for consultation)
- dedicated case workers for “hard-to-access” clients.

The following general themes were also identified (Furin, Shutts, Keshavjee 2008):

- patient-centred care
- continuity of care and a continuum of care
- self management
- case management
- integrated, multi-disciplinary team based approaches
- coordinated delivery system

- response to non-clinical health determinants (housing, employment etc) and the importance of support services
- effective information management system.

All work done in this area however has highlighted the absence of data to inform policy makers, funders and providers and the need for further research.

Current models of HIV service delivery in Australia

HIV care in Australia is provided in many ways, by different service providers, under a variety of models. Almost all jurisdictions have reviewed or developed models for HIV service delivery recently.

Common themes have emerged about the shift in care needs for the majority of people living with HIV who are living longer and better lives, which will, as a consequence of improved treatment and side effects, become more complex. HIV clinical care is being provided by specialist centres to a spectrum of services in the community by practitioners with varying levels of training and expertise in HIV, who are supported by experts to varying degrees. Not surprisingly, chronic care models which emphasise planning, coordination, multidisciplinary, integrated and patient centred approaches are borrowed and applied to aspects of contemporary and future HIV care.

Similarly it is recognised that to succeed these changing models of care must be supported by new(er) and different patient information management systems and communication systems. Other organisational and infrastructural supports (policy, legislation, partnerships etc) are necessary.


It is clear that no one model is appropriate to suit all populations. Primary Health Care models however that have effectively delivered services for people in rural and remote areas include the following:

- discrete services, such as general practitioner models for rural towns
- integrated services, such as the Multi-Purpose Services (MPS) program
- comprehensive primary health care services, as exemplified by some Aboriginal community controlled health services
- outreach services, including successful hub-and-spoke models delivering services to smaller, more isolated communities
- virtual outreach services, such as tele-health.

Other factors, such as health literacy and communication of health information take on greater roles with geographically and socio-culturally marginalised populations. Issues such as fuel costs and public transport are also important. This highlights the significance of effective electronic communication strategies and of the management of health information as well as the need to address other determinants of health. Initiatives like the Isolated Patients Transport Assistance Scheme (IPTAS) should be considered where alternatives do not exist.

Existing HIV clinical services

This paper acknowledged that in Australia a wide variety of services and service models are implemented, which differed based on whether delivered in urban (State capital cities), regional or rural settings and



access to these services has been reported to be problematic by some States/Territories. A relatively small number of high HIV case load GPs currently care for large numbers of HIV patients with complex needs. It is ASHM's experience that the number of high HIV case load GPs and practices is static or declining; it is a continual challenge to recruit and retain professionals for HIV and viral hepatitis clinical (including prescribing) training. The objective of this report was to provide a map of existing Australian clinical services, GP's, s100 prescribers and compare this with where HIV diagnoses are happening and provide an analysis of this data. What this paper highlights is the need for data which measures occasions of service use over time to characterise "intermittent" and "regular low level" service demand.

Workforce

The roles, supply, trends, recruitment and capacity to deliver HIV services were described and analysed. The issues related to the rural and remote health workforce are highlighted here. This report looked at the different roles and responsibilities of a small number of health professionals to determine what impact their availability has on the access to prevention, care, support and treatment health services by people living with HIV. Special attention was paid to the supply and trends in rural and remote workforce, the Aboriginal Health Workforce and access to health care by culturally and linguistically diverse (CALD) people.

Workplace changes do not occur in a vacuum. There must be an understanding of the complex factors involved in supporting health care professionals to work in a positive and attractive environment, and when a positive and attractive environment is unlikely to occur, as happens, other incentives or benefits must be considered. The process must have across the board policy support—all governments and all of government. Funding must be available and funding priorities clear. Professionals must have opportunities for training and development, where their roles can be backfilled if required. Recruitment and retention can be improved by understanding the non-work related pressures that exist: social, cultural, family and financial responsibilities that may be barriers, or enablers to attracting and retaining staff.

The evidence base for effective strategies for recruitment and retention of health professionals in different areas is underdeveloped in Australia. As outlined in the Cochrane report (2009), there are no well designed, unbiased studies to support any of the numerous interventions which have been implemented to address the shortage of health care professionals practicing in underserved areas. Importantly, various strategies aimed at reducing the mal-distribution of health care professionals have been poorly quantified in the short or long term.

Furthermore, evidence suggests that newer workforce roles (such as nurse practitioners and physician assistants) may better support health professionals to meet demands created by an increasing complex and ageing HIV population. We have little experience of the wider roles that nurse practitioners can take on, and none of physician assistants. Certainly, it appears that in many general practice based services, clinical and administrative duties could be devolved to others. This is particularly relevant in rural and remote settings, where flexibility in service delivery models and a more generally trained workforce are essential in meeting the needs of a diverse (geographical, socially, economically and demographically) population.

As well as evaluating the efficacy of these positions (physician assistants particularly) and currently there are trials under way in South Australia and Queensland; the process of incorporating new professionals, or changed professional responsibilities needs to be carefully assessed. Task substitution has received some attention in Australia, however in practice it is often discouraged because the provision of certain tasks by other professionals does not attract an MBS subsidy and out-of-pocket costs for patients who choose to use their services would often be higher, even though the overall cost to the community would be lower. Unfortunately, this results in less cost-effective provision of services and medical practitioners'

time being diverted away from the delivery of other potentially more beneficial services (such as the referral of a patients to an allied health HIV provider) (Productivity Commission Report, 2005). The introduction of a new layer of professionals may well stimulate professional territorialism with results that are counterproductive to the objective of improving health outcomes.

Research indicates that there are a range of issues related to the inherent barriers to recruitment and retention of health care worker in rural and remote Australia. Included are “limited locum services; restricted access to peer support; fewer professional development opportunities than in the major population centres; limited opportunities for spouses and children; inadequate accommodation; lack of remuneration commensurate to qualifications and the degree of isolation (Access Economics 2002, cited in Productivity Commission Research Report 2005, pg. 348). Dr. Pashen, (personal communication, 23 February 2009), President of the Royal Australian College of Rural and Remote Medicine (ACRRM) maintained that it is difficult to compete with urban hospitals that offer candidates a structured career path for professional development. A summary of the workforce planning strategies recommended by the Australian Primary Health Care Institute, Systemic Review of Primary Health Care Delivery Models in Rural and Remote Australia (1993-2006) to address these issues with regard to the recruitment and retention of the health workforce in rural and remote regions are outlined below:

- a sufficient number and range of appropriately trained health professionals to meet community needs
- a recruitment strategy to address professional and personal needs, including minimal start-up costs and capital investment for staff, housing, leave, appropriate workload, and spouse and family support
- a retention strategy addressing professional support, continuing professional development (including travel costs and leave packages), and sustainable after-hours and on-call arrangements
- feasible succession planning strategies.

Other improvements in education and training include:

- augmenting on the job with time for intensive training
- matching any initiative to RACGP and equivalent programs and providing time off/locum support to allow for training
- intensive training for overseas trained doctors going into high priority areas
- competency based education and the dovetailing with registered training organisations and higher education offerings
- the need for medical and nursing and allied health education to be better incorporated into Bradley review and implications for education service providers
- greater collaboration between states and territories and institutions so that prior learning and specialised courses can build to professional and academic qualifications
- a similar TESL (training, education and study leave) arrangement for GPs as with hospital specialists to support continuing education
- there is a role for competency based training if this can be linked to and provide advanced standing for post graduate qualifications

- training arranged by the Divisions of General Practice should be linked with hospital clinics and community groups for an integrated approach to training (this happens with some divisions but not with most)
- use of supported clinical placements to promote inter-disciplinary learning
- training for general health workforce (i.e. aged care workers, practice nurses) in HIV is needed, which GPs or specialists may not have time to address in a patients appointment. Specific training needs include addressing stigma and discrimination, health promotion, risk prevention, behaviour change, anxiety/depression in relation to HIV, cognitive changes/ dementia, living with chronic health issue (coping strategies to deal with peaks and troughs of living with HIV) managing physical manifestations (body image, lethargy) and assertiveness skills required for self management
- flexibility is required when providing training, and must be tailored to the needs of each discipline. For example practice nurses may prefer trainings in the evenings, whereas at CNCs working in urban hospital setting may feel that training should during regular working hours. In rural and remote settings where transport is a barrier, preference may be for some face to face clinical component in the closest town, combined with distance education online modules
- the World Health Report (2006) provides a framework called the “working lifespan” approach which has been applied in some workforce settings. This model requires a whole government approach to planning and action. RACGP uses this model in their *learning life* stage approach to general practitioner’s learning. Students may enter this training path at different parts of the learning lifecycle, depending on their previous levels of educational qualifications (for example an international medical graduate). Is there room to adapt this model to other workforce areas such as Aboriginal Primary Health Care Workers or Practice Nurses, allowing flexibility and valuing previous work and non-work experiences?
- interdisciplinary training in cultural competency is required by all health professionals to meet the needs of the CALD communities affected by HIV. The National Health and Medical Research Council (2005) released a discussion paper entitled *Increasing Cultural Competency for Healthier Living and Environment* which provides a useful guide for health professionals who provide services to CALD communities. The project findings led to the development of a national guide or model for policy, partnerships and participation aimed at improving the cultural competence of the health sector and partners working with culturally and linguistically diverse communities in Australia.

Implementation strategy to respond to these issues as priority areas

The following priorities were identified by the MACSD Advisory Panel (5/6 March 2009) to be included in the next National Strategy.

1. Shared Care:
 - Implement a series of demonstration projects aimed at exploring mechanisms for facilitating and delivering shared care in the community
 - Determine the features of community provided shared care & who is referred for this level care:
 - level of patient need
 - level of practitioner training and where delivered

- role and frequency of specialist review
 - other contributors (nursing, practice nursing, CBO)
 - Develop a range of community provider supports
 - Cost, document and promulgate information about these
 - Explore strategies for sustainable funding
 - Data collected from all enrolees & regularly contributed to AHOD/ARCSHS data sets for example
2. High Case load s100 prescribers:
- Develop and implement a series of tailored supportive solutions to support individual high caseload community practices
 - Cost, document and promulgate information about these
 - Gather data and contribute to NCHSR/NHMRC project on barriers
 - Explore strategies for sustainable funding
 - Data collected from all enrolees & regularly contributed to ADOH/ARCSHS data sets for example
3. Nurse based initiative
- Explore, implement and evaluate a range of nurse based strategies aimed at increasing access to clinical service delivery
 - These may include:
 - Practice nursing
 - Nurse practitioners
 - Community based nurse models
 - Cost, document and promulgate information about these
 - Explore strategies for sustainable funding
 - Data collected from all enrolees & regularly contributed to ADOH/ARCSHS data sets

Supporting and enabling recommendations:

- Essential to the success of the above recommendations is the:
 - Inclusion of additional priorities in the next National HIV Strategy
 - Support of routine and longitudinal data sets such as ARCSHS. Suggestion of occasions of service measures study- tracking changes in patterns of service use over time to characterise "intermittent" and "regular low level" service demand by demographic characteristics of PLWHA
 - The expansion of the AHOD data set

Other priorities:

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

Conclusion

HIV in Australia can generally be considered a manageable chronic disease, the clinical care needs of consumers for most of the “journey” are at the lower end of the spectrum; this changes as people age and develop co-morbid conditions and complications of their HIV and their HIV therapy.

The demonstration projects listed above will form part of the implementation and final report to be submitted to the Commonwealth Department of Health and Ageing at the end of April 2009. The first four have been highlighted as priority projects for inclusion into the 6th National Strategy. The priority demonstration projects have particular relevance in the management of complex and stigmatising conditions outside urban Australia. The shared care model will increase the capacity of GPs to improve the clinical outcomes of HIV positive people and supports alternative models, including the nurse practitioners and practice nurse which may be more relevant in rural and remote settings. This project would target GPs with an interest in providing basic HIV care (not full s100 prescribing) in formal partnership with HIV specialists in urban, rural and regional settings.

The workforce paper highlights the severe shortage of s100 prescribers in rural and remote regions of Australia. The 2nd demonstration project will look into the specific difficulties faced by high case load s100 prescriber in providing clinical services. This project aims to investigate these issues and their impact on service delivery and recommend solutions. This nurse based initiative study will also have significant relevance to rural and remote communities where nurse led models of care are more prevalent. This demonstration project aims to gain a better understanding of nursing professional contribution to HIV positive client management in rural and urban settings.

Finally, worth highlighting here is the time of diagnosis project which will ensure GPs who rarely diagnose HIV (accounting for nearly 50% of new diagnoses in Australia) are contacted immediately after making an HIV diagnosis with an information pack for the doctor and the patient. This will be of particular relevance to GPs in rural and remote settings who do not have high case loads of HIV positive people and would benefit from information and referral service at the time of diagnosis. This project is ready to be trialed in Western Australia.

In conclusion, the background papers support that an effective model of care for HIV positive people in Australia needs to be supported by an expansion of multidisciplinary teams that are patient-centred and integrated to provide comprehensive care, particularly for complex (and chronic) conditions. This requires the reallocation of responsibilities so that service delivery mechanisms match the level of specialist/generalist care needed on a case by case or casemix basis. ASHM advocates for a future national health system which delivers “high quality education and training for both new and existing

workforce". This requires enormous support, beyond the development of high quality courses, and systems that underpin workforce training, recruitment and retention must be maintained and developed.

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Presenters

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