



Positive Services Forum Report

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Positive Services Forum Report

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Glossary

ACON	ACON (formerly AIDS Council of NSW)
AFAO	Australian Federation of AIDS Organisations
APOH	Association for the Promotion of Oral Health
ASHM	Australasian Society for HIV Medicine
BGF	Bobby Goldsmith Foundation
BBVSS	Blood Borne Viruses and Sexually Transmissible Infections Sub-Committee
CALD	Culturally and Linguistically Diverse
CDP	Commonwealth Dental Plan
CDHP	Commonwealth Dental Health Program
COAG	Council of Australian Governments
EPC	Enhanced Primary Care
GP	General (Medical) Practitioner
HAART	Highly Active Anti-Retroviral Therapy
HACC	Home and Community Care
HIV	Human Immunodeficiency Virus
HREOC	Australian Human Rights and Equal Opportunity Commission
GLBT	Gay, Lesbian, Bisexual, Transgender
HALC	HIV/AIDS Legal Centre
MCBVSS	Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmissible Infections
NAPWA	National Association of People Living with HIV AIDS
NCOSS	The Council of Social Services of NSW
NGO	Non Government Organisation
PozHets	Positive Heterosexuals
S100	S100 Highly Specialised Drugs Program

Report on the Positive Services Forum

Introduction

The Positive Services Forum was held in Sydney in 2009 to facilitate information sharing and networking opportunities for people providing care and support services to people living with HIV. The Forum explored and promoted practices with demonstrated success in providing services for people living with HIV. Some 60 staff of key HIV service provision agencies around Australia attended the Forum.

The Positive Services Forum clearly revealed the increasingly complex environment in which HIV service providers work. The experience of living with HIV has changed dramatically for most in the post-HAART era, and more than ever, service providers are required to differentially target populations of people living with HIV and to manage a complex range of issues. Notably, most of those now accessing HIV services present with multiple and complex needs. HIV may or may not be the primary presenting issue, and may be a co-factor with issues around housing, alcohol and other drug use, mental health, relationships, isolation, disclosure or poverty. Those clients require a sustained and sophisticated response, including use of HIV services' strong networks with other mainstream service providers, which in turn requires mainstream services' competency in addressing HIV. Some people, who may have lived with HIV for some time, access services from time to time as their circumstances and needs change. Ensuring relevance of those services is vital. Importantly, many of the more than 17 000 people in Australia living with HIV no longer access HIV services outside clinical care, which is largely managed by their treating doctors. They are a population most effectively targeted by social marketing campaigns addressing emerging issues (such as the intersection of smoking and HIV), and other issues that most people living with HIV navigate in their everyday lives. Effective targeting of this diverse and increasing population remains challenging.

As people with HIV live longer, the population of people living with HIV is ageing. Many have lived with HIV for a long time. People are facing similar issues to other aging populations, issues specific to the impact of HIV on the ageing process, and issues relating to the intersection of behavioural factors, HIV and ageing: such as smoking (with significantly higher rates among people living with HIV than in the general population) as a risk factor for lung cancer, or anal sex and consequent infection with human papillomavirus as an infective agent linked to anal cancer. As many of those living with HIV are gay or men who have sex with men, aging is also frequently impacted by both HIV status and sexuality. The capacity of mainstream aged care service providers in relation to sexuality and HIV positive status will become increasingly important.

HIV services are addressing issues around limited employability and the accumulation of debt, which has a differential impact now that many understand they are likely to live a long life while HIV infected. The changing social 'meaning' of HIV has also impacted peer support and influence, with HIV positive people generally knowing fewer positive people than a decade ago. Many older people have left urban environments and positive people are now more dispersed through the general population. HIV is less critical as it relates to 'identity', with many prioritizing gender, sexuality, family and other basis of identification. Increasingly, new infections have been diagnosed among people from culturally and linguistically diverse communities. HIV services must remain relevant to young people who are without the knowledge and community cohesion triggered by the impact of HIV in the 1980s and 1990s.

There are increases in the percentage of HIV positive people who have an undetectable viral load, impacting their sense of well being and understanding of what it means to have HIV. There is continuing tension between those conceptualizing HIV as a chronic disease that is manageable with effective treatments, and those who recognise that many continue to experience illness and debilitating side effects or limited effectiveness of increasingly complex treatments. Specialist high caseload, S100 prescribing doctors are under increased caseload pressure as the number of people living (longer) with HIV increases. The proportion of people living with HIV using anti-anxiety and anti-depressant medication is higher than in the general population, with some people living with HIV experiencing significant distress and impairment as a result of mental illness.

Given the complexity of HIV, it is fortunate that Australian HIV service providers have access to expert behavioural, social and epidemiological research to complement their understanding of HIV gained through grass roots service provision. Many working in the sector are highly experienced across a range of fields, and HIV-based service networks remain strong. The Positive Service Forum clearly demonstrated service providers' capacity and commitment to continue delivering an effective HIV response.

This report provides a summary of presentations and forum discussion from the Positive Services Forum. These summaries retain the style of authors' oral presentations, varying from formal academic presentations to informal, personable accounts of service providers' work. Together, they provide a unique snapshot of many of the key issues and strategies current to HIV service provision as we turn our minds to developing an effective HIV response for the next decade.

Complete recordings of individual presentations are available on the AFAO website at http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=169&pxsc=&pxsgc=&id=732.

Background and Environment

1. Changing Service Provision in a Context of Changing Need

Russell Westacott: Director of Client Services, ACON

The experience of living with HIV has changed dramatically for most in the post-HAART era. Most people living with HIV do not access HIV services regularly. The most regular service accessed is quarterly blood tests and subsequent results from their GP. Then, if necessary, the collection of prescribed medication from hospital pharmacies. Beyond this most people with HIV do not access HIV services at either community-based or mainstream providers on a regular basis.

In NSW, there are more than 10,000 people living with HIV. ACON is the country's largest community-based service provider to people with HIV, seeing some 2,000 people living with HIV a year for HIV-related services. Other ACON programs may see some people living with HIV but these people are not presenting for HIV-related issues.

Those we see most - The people we see most often are probably those who present with a range of issues - multiple and often complex needs. HIV is not necessarily the presenting issue but a co-factor with issues such as housing and accommodation (including homelessness), alcohol and other drug issues, mental health issues (including depression and anxiety), issues around disclosure, relationships, domestic violence, social isolation, lack of resources to adequately feed oneself, as well as other issues connected to poverty.

They are often people who are socially marginalized within our community. We know from work we do on interagencies and collaborations with other service providers that these people not only seek services from ACON but from other providers. It is essential that we continue to plan for and maximize our efforts targeting this group of people living with HIV. We need to continue to ensure that people are fully supported so that they do not fall through the proverbial gap. We need to not only maintain our scope of services but work with mainstream providers to ensure that these people with HIV are adequately serviced across all the various service options available.

At ACON, we have recently collaborated with the Bobby Goldsmith Foundation to provide Sydney's Luncheon Club service to around 700 disadvantaged and marginalized people with HIV. Over the last twelve months, under the new co-management arrangement, the service has been transformed from a welfare dependent model to a service that connects individuals with a range of service options and health promotion activities. In doing so, we make use of the opportunity to engage people on one issue – in this case the free lunch – but we offer other service options alongside the primary service. This means that people can now come together for lunch and to break social isolation but also be introduced to diet and nutrition classes, and understand what other providers have to offer through our in-reach programs. In short we offer a program that connects people to a web of service options.

One of our most significant challenges is the adequacy of mental health services. Although we work with people who are HIV-positive who present with mental health issues, it is often determined that we are not best-equipped to work with people presenting with complex issues. Mental health services are. However it is not uncommon for HIV-positive people who we referred to mental health services to come back to ACON as the mental health service may be under-resourced, and the mental health service has decided an HIV service is better than no service at all.

Obviously the problem with this scenario is that the client bounces from service to service. We need to advocate on two levels:

- Firstly, we must ensure that mental health services deal as best they can with HIV-positive people who present with mental health issues. While these mainstream providers have their own resourcing issues, it should not be the case that HIV-positive people bounce back to HIV services without an adequate assessment and service plan. A recent example at ACON involved a person who was having difficulties adhering to their medication. ACON staff involved the local mental health service. The adherence issue centred on mental health medications not HIV meds. Nonetheless the person was back at the Positive Living Centre in a matter of days and still non-compliant with his mental health treatment. Basically nothing was done for him. This is unacceptable.

- Secondly, advocacy needs to be at a macro-level, targeting adequate resourcing of the mental health sector so that it can respond appropriately. We need to be advocating for 'whole-of-government' responses so that our constituents are well-served wherever they go for services. This is a big ask but nonetheless it is something we should be a part of.

When working with people who present with multiple and often complex needs, the HIV sector needs to rely on strong partnerships and collaborations.

Those we see intermittently - These are a group who have been living with HIV for an extended period of time. Some thought they would die of AIDS but they now have been living with HIV since before the HAART-era. While the successes of HIV treatments are now well-known, people living longer-term with HIV still find themselves at a cross-road. The narrative goes something like this: 'OK, so I thought I was going to die, I planned to die, I haven't died and now I need a plan for the future I didn't think I was going to have'. Supporting people around this type of life juncture has been and remains an important area of service delivery for AIDS councils and Positive Living Centres. We need to assist people to navigate significant life decisions such as investing in longer-term strategies, returning to work and study, re-engaging with life and relationships, as well as planning to grow old as happily and contentedly as possible.

Programs such as *Life Coaching* as well as other services assisting people in better self-planning and preparedness are vital. Engaging with people intensively at the time they choose to journey through this territory is a necessary aspect of support. At ACON, our *Life Coaching* program is expanding due to the enormous success of its initial implementation. To ensure its ongoing success, we must offer a responsive service that concentrates its focus on motivating those individuals who are ready to create change in their own life. It is important that this program serves the many who need it and does not slip into a model that encourages a form of longer-term dependency. In short, *Life Coaching* needs to be short, sharp and targeted. It needs to be available to as broad a group of people with HIV as possible who are at that life juncture, and it needs to work on a model that empowers individuals so they can decide and embark on their own journey in addressing their life goals.

Those we don't or rarely see - These are the vast majority of people living with HIV, however, there are a variety of issues we can target in relation to this population through social marketing. For example, health promotion community-reach campaigns that address better health and well-being such as prevention of cardio-vascular and diabetes conditions, smoking cessation etc. Also, campaigns that acknowledge sex positivity while addressing the challenges of disclosure. These are the types of issues it is probably fair to say most people living with HIV – regardless of service connection – need to navigate in their day-to-day life.

The other service issue sits within mainstream providers. The service that virtually all people living with HIV receive on a regular basis is blood tests, results and collection of medications. NAPWA have been doing some work in this area through their *Improved Models of Access and Clinical Service Delivery* project. While this project looks at the full range of clinical services people with HIV might receive – from GPs to hospital visits – it ensures that clinical service delivery to most people with HIV is examined for the purpose of further streamlining and improving.

Access to S100 medications will be improved as part of this project. This is a necessary area of work on which the sector can provide more focus, resulting in benefit to **most** people with HIV. While S100 medications are funded through federal funding streams and therefore reform in this area is partially federally focussed, S100 medications are dispensed through state-based hospital pharmacies. Reform can occur at a state-level, and advocacy in each state and territory might result in outcomes such as the community pharmacy dispensing arrangement in Adelaide.

In NSW we have been working closely with Area Health Services and are hopeful we might see reform by way of pilot community pharmacy dispensing arrangements. If this comes to fruition, we will see late opening satellite pharmacies dispensing HIV medications at accessible locations and at convenient times. Reform in this area will see better service delivery to the bulk of people living with HIV.

In closing, when responding to services for people with HIV we need to consider the spectrum of service needs of this population including those who require intensive services, those who require occasional services, and those we don't

see. There are scenarios where mainstream providers are best equipped to offer greater support. Our organisations should be involved in advocacy around the reform of certain mainstream services so that people with HIV can effectively access all the services they require.

2. State of the Positive Nation – Data from Futures 1 to 5

Jeffrey Grierson: Senior Research Fellow, ARCSHS

Data from Futures 1 to 5

At times, the discourse around people with HIV characterises people living with HIV as living within a fourth world country of their own. In fact, the experience of living with HIV is diverse, with very, very different experiences of living with HIV. Those coming through services are often those of highest need but we have to consider diversity and people's full range of experiences.

ARCSHS' *HIV Futures* reports (numbers 1 to 5), highlight some important trends: how we got here and where we're going. We need to be thinking about:

- Issues around an aging population
- Generational experiences of HIV – the experience of being diagnosed in 2009 is very different from diagnoses in 1985. How does that shape service access? How does it affect how people see themselves? It's not about youth, and while part of it is about being younger, there are other differences as well. What is it going to be like to be diagnosed in 2029?
- Complications and comorbidities – and if you combine comorbidities with ageing or with Hep C or with sexual health, it has different meanings
- Living long term with HIV
- Geographic shifts – there is general mobility in the Australian populations and populations from which positive people come (gay men have been particularly mobile). People living with HIV are moving in and out of rural areas. These patterns are affected by economic situation, particularly home ownership. How does it affect people living long term with HIV?
- Mental health issues – there have been changes in the type of mental health issues arising for different populations over the epidemic. Early on they were sharp mental health issues. Now there are more mixed issues, including complex and overlapping mental health issues, intermittent issues and those that build up. Don't necessarily have the expertise in the sector.
- Employment changes – the sector must respond
- Social trends – What does 'HIV community' mean? Who does it mean something to? This is particularly important when marketing services and understanding why people come to services.
- Community attitudes – there are shifts in stigma and in community attitudes. Stigma has not gone away. It is changed but more intense. ARCSHS has recently surveyed gay and lesbian community attitudes on positive people and expectations around disclosure of HIV status, and the news is not great: some v. negative attitudes.
- Criminalisation
- Modes of engagement with positive services have changed over the epidemic. The way people engage has changed and proportion of people engaging has decreased but they are using multiple services and using them intensely.

If you look at HIV Futures reports 1 to 5, you see changes in:

- Age distribution – We have seen an aging population. That means many treatments are working and more people are staying alive but that has implications in terms of services. For example, how to deal with young people and with those who are more mature and experienced? Age differs by region. Most HIV positive people live in inner cities (reflecting Australian population trends) but more young people are likely to be the inner city, with more older positive people are living in regional and rural areas.

- Employment – Along with improvements in treatment, fewer people are not working, with a shift to greater hours of part time employment (not full employment) which has real implications for people’s ability to access services, particularly how much they can pay. Government benefits remain a primary source of income. There are not large populations of positive people on high incomes. Debt remains a critical issue, particularly the experience of living long term on debt. What does it mean to be planning for short future if with accumulated debt?
- Peer contact - The degree of contact people have with other positive people has declined. Few know no one else with HIV but more people know fewer positive people. People with HIV are more dispersed throughout the population, which is critical if thinking about peer influence.
- Social identity – How important is HIV status to a sense of self? Some consider their HIV status essential - around 15 to 20% of positive people completely identify around it. That is far fewer than prioritise sexuality, gender, and family. Others consider HIV barely relevant, and that percentage has increased over time. That is important in terms of marketing services.
- Sex and relationships – beyond infection. We have to think about sex in terms of social wellbeing, intimacy, connectedness to others, and pleasure. 30% of people in the most recent survey have no sex at all – a statistic that is not changing. It crosses age ranges, wellness, etc. Around 46% have a regular partnership (some don’t have sex). Almost ½ have a positive partner. People are likely to have very different experiences re: what it means about managing HIV (not just sex) within a relationship.
- Health status – People have a range of health experiences. Few consider their health poor, although notably that definition has different meanings for different people e.g. someone who has had experience of grave health may measure health differently from someone recently diagnosed with little experience of ill health). Few people considering their ‘wellbeing’ very bad or excellent.
- Clinical – There is an increase in the proportion of people who report their viral load as undetectable, so we must question how that impacts sense of self and a person’s identification with HIV.
- Mental health – Data has not changed much but what we are seeing now is more concurrent mental health conditions. A much higher proportion of people living with HIV are using anti-depressants and anti-anxiety medication than in the general population.
- Medication - Anti retroviral uptake in Australia has not changed much. There is a very high uptake by international standards and few who have dropped it, indicating high levels of confidence in its effectiveness.
- Clinical information – Clinical sites remain key (e.g. doctors) but also community organisations and their publications. In some ways, social sources are considered more important than clinical sources, but most say doctor are their key source of information. Many now are using services that are not HIV related so need to check those services know enough HIV. Around 40% of people are using HIV services as a point of social contact with other positive people.
- We haven’t seen dramatic changes in service use, but priorities remain: 1. financial assistance, 2. treatment advice, 3. social contact, and 4. peer support.

We need to think not only about those currently accessing services, but about what the evidence shows and how services might effectively address the needs of all PLHIV.

3. Current Directions in Aged Care

Mark Gaukroger, Assistant Director, Department of Aged Care

Much has been written about the impact of the aging population on the Australian community. An aging population translates into higher morbidity, lifestyle disease and new infectious disease. It is estimated that by 2040, 24% of the

population will be over 64 compared to 12% in 2005. There are growing numbers of people over 100 years of age and many still living in their own homes. These demographics coupled with changes in health care delivery provide significant challenges to government and the community. There is definitely a drive for more community based care rather than residential or hospital based care, with a greater emphasis on care coordination and case management. Carers are becoming increasingly consumer driven on self management in terms of chronic disease. There is a distinct move to primary care led services and distinct use of home care.

Community Care - There is a range of community care administered by Australian government to allow older people to remain in their homes for as long as is reasonably possible. In 2009/2010, the Australian Government will provide \$2.2 billion in funding to support people living in the community: an increase of over 9% on last year's budget. Essentially, there are four levels of aged care:

- HAC Program - the Australian Government provides approximately 60% of program funding and plays a broad strategic policy role. Day to day administration is undertaken by state governments. Services include domestic assistance, and nursing to some 830,000 people who are aged or disabled and their carers
- Community Aged Care (CAG) packages – More than 40,000 packages valued at approximately \$12,000 each are allocated around Australia. They provide a higher level of care than HAC and are considered an alternative to low level residential care.
- Extended Aged Care at Home (EACH) package – EACH provides a higher level of support than CAG packages, with each EACH package valued at approximately \$42,000. They cover domestic assistance and personal care. Currently 4,300 are available in the Australian community.
- Extended Aged Care at Home: Dementia (EACH D) Package – These support people with dementia. There are approximately 2000 packages available.

Carers - It is now well recognised that carers make a strong contribution to society, and that support for carers should be a priority. Almost 2.6 million Australians provide care for family members, of whom some 500,000 are primary carers. Australians over the age of 55 contribute approx \$75 billion annually in care and voluntary assistance. Carer support includes the Commonwealth Care Link Program – which provides a single linking point of contact (Commonwealth Care Link Centre) for service providers, general practitioners, etc. wanting to understand care options. These assist carers to source short term and emergency respite. There are 600 respite centres throughout Australia, and 30 demonstration day respite services have recently been established. The National Carer Counselling Service provides support through state and territory carer associations.

In May 2008, the Minister for Community Affairs, the Hon Jenny Macklin MP, asked the House of Representatives Standing Committee to enquire into and report on better support for carers. Some 1300 submissions were received. *Who Cares?*, the name of the report, has 50 recommendations for Government, many of which are relevant for The Department of Health and Aging (DOHA). Key DOHA related recommendations include:

- extending the access points demonstration project to include mental health and disability. The Access Point Demonstration project is work undertaken to simplify assessments (a point approved by COAG in 2006). Trying to access government services can be very complicated so this hopes to reform and simplify that process. The first step in trying to implement this initiative is establishing access points for people and their carers. These access points will streamline entry and ensure consistency of assessments. There are currently nine access points in seven states. They will be evaluated in mid 2009, which will inform rollout of more centres.
- developing the Carer Eligibility Assessment Tool (CENA). Over the past few years, the Department has been developing a tool to compliment the client assessment tool (ACNA). In 2007, work commenced on the revised version of the CENA/ Quality assessment needs to be undertaken for carer and care recipients.

Other recommendations included:

- Consumer directed care pilots
- Nationally consistent data

- Increases in recurrent funding for respite services

The government has (in principle) three months to respond to these recommendations, and DOHA is working closely with FACSIA, the lead agency.

Access and Assessment – The Government is committed to full access for all Australians. People should be assessed and eligibility granted according to need. So, it is important to note that even though a person might fall within categories, HAC is not an entitlement program and not guaranteed, as access is based on relative need. Current policy places responsibility for determining access with service providers. Some 115 teams provide comprehensive, multi-disciplinary assessment.

On 10 October, the Hon. Justine Elliot, Minister for Aging, announced a Charter of Rights for disabilities and community care. The Charter is designed to engage consumers around the kind of care they will receive in a way they understand. It has been recommended the charter be entrenched through the *Aged Care Act* so it will be enforceable. We hope this might happen by October 2009.

The Australian Government is committed to the responsibility it has to older persons. In Madrid in 2002, the second world Assembly on Aging delivered recommendations for national frameworks comprising three priority directions:

- Older persons and development
- Advancing health and well being into old age
- Ensuring enabling and supportive environments.

The Australian Government is resolved to follow these priorities. All levels (govt and community) share responsibilities. Funding and regulation is predominantly the role of the Australian Government. The Government is committed to the reform of the aged care sector. The focus of these reforms will be on providing culturally appropriate care, improving the skills of the aged care workforce, and innovative and flexible services. The Government's approach is to work collaboratively across three levels of government and with the community sector to provide consistent and responsive aged care services. The government also provides a regulatory framework.

Some people have special needs including Aboriginal and Torres Strait Islander communities, those who live rurally and remotely, those who are financially and socially disadvantaged and veterans. These special needs provisions are consistent with the Social Inclusion agenda.

Tremendous effort is being undertaken to address issues associated with the aging population, both by government and the community sector. AFAO has a significant role and has advocated to meet needs of these communities.

4. Advocacy for People Living with HIV in Mainstream Services

Lance Feeney: Positive Life

This presentation provides an overview of the NSW Systemic Advocacy Project: why it was established, what it hopes to achieve, the issues that we've worked on in the last 12 months, and our plans for the future. It is the only state based PLWHA advocacy project in Australia.

In 2004, Positive Life sought to build its capacity in systemic advocacy. The Supported Accommodation Review conducted by NSW Health in 2006 identified the need to remove barriers to mainstream services, and to develop joint strategies across agencies to achieve agreed objectives. Ensuring that programs adapt to the changing health and service needs of people with HIV was and is a key objective for the project. In July 2008, Positive Life established the Systemic Advocacy Project with ongoing funding from HSW Health.

The project draws on a range of standard advocacy tools including; research, consultation, collaboration, communication, community mobilisation and lobbying. Stakeholders and community consultations (including community forums, periodic Board Advisory Groups, metro and regional consultations) identify and prioritise issues. Analysis and

discussion of research, with input from service providers and people with HIV, provide the strategic framework. At the same time, representation to government and non-government agencies enables Positive Life to participate in a range of relevant policy discussions and government inquiries, and to keep abreast of public policy change.

Priorities - Priorities fall into two basic categories and juggling these priorities has become an essential part of the role

- **Long term** - access to quality clinical care, housing, aged care, income support and supported accommodation, are long term advocacy objectives for this project.
- **Opportunistic** (time related) – arising, for example, because of changes in public policy, funding, guidelines, changing need, etc. These include improved S100 dispensing for working people, better preventive and restorative oral health services, a better functioning health care complaints mechanism and the inquiry into the *Health Care Complaints Act 1993* and the Health Care Complaints Commission; and the differential impacts of same sex relationship recognition in 2009.

Recent areas of focus:

1. **Same Sex Legislative impacts** - Positive Life understood very early that Social Security changes would negatively impact some positive people, so commissioned research to identify and understand the implications. With Welfare Rights (who have been a tremendous help), Positive Life has made submissions to the HREOC Inquiry and to the Federal Government. HREOC was asked to host a forum attended by community reps and key Canberra Centrelink staff to discuss the potential implications of the legislation. Positive Life encouraged pick-up by ACON and NAPWA as leading representative organisations, and took up membership on the Centrelink Community Reference Group. Positive life provided early information to inform the community about the potential impacts of legislative changes, in *Talkabout* and on the Positive Life website. ACON and GLBT National Health Alliance (NHA) took-up the issue, with a joint community position developed and promoted by NHA, and joint lobbying undertaken in Canberra. NHA and the Welfare Rights Network were funded by the Federal Government to undertake a community education campaign and individual advocacy work in response to joint community demands.
2. **Oral Health and access to dental services in NSW** - This remains a major area of service delivery. The EPC Medicare dental scheme is providing significant benefit to people with HIV, however, the public policy environment is uncertain. Funding for public dental service in NSW is on hold until a decision is made at Federal Level.

Positive Life sits on the Oral Health Special Needs and Specialists Advisory Group, which advises the Chief Dental Officer on the needs and potential programmatic responses to oral health needs of people with HIV and special needs (including people with HIV). This Group reviewed NSW Chronic Conditions and Special Needs Dentistry Program which forms a key component of NSW Health's implementation plan for Commonwealth Dental Health Program funds (which will be approximately \$1.5 million per annum for 3 yrs, although the Commonwealth is not releasing funding until the EPC program is wound up). Other policy implementation and communication has been undertaken with the NSW Director General of Health.

Positive Life is also part of the Oral Health Alliance, which recently developed the 'Access to dental services amongst clients of non-government human service organisations' report. The report highlights the disparity between the oral health outcomes of those who are able to afford to pay for dental services and those who are reliant on public dental services. The report (launched at NSW Parliament House, April 2009) made a number of recommendations and called for additional funding. The NSW Minister for Health will respond.

There is ongoing discussion between the Area Health Services and the AIDS and Infectious Diseases Branch of NSW Health regarding the reallocation of '2.3 program' funding (in response to the HIV State-Wide Service Review) for the provision of services to improve access for public dental service provided by area health services for people with HIV. As a result of this work, Positive Life has developed valuable relationships with the Australian Dental Association (NSW Branch); Sydney Dental Hospital exec staff; and the Association for the Promotion of Oral Health.

3. **HIV and Media** - Getting uptake of HIV issues in the mainstream media has always presented a challenge. In 2008, NSW Health funded a Project to raise the profile of HIV in the media. Positive Life ran a Media Breakfast prior to World Aids Day to assist journalists to better understand and report on HIV and HIV related issues. Mainstream and community journalists were targeted. Specialist presenters provided background to a comprehensive media information package. NSW Health requested the program re-run with further development to target journalists writing for gay print and online media, print and radio health journalists, ethnic media journalists and Sydney based political advisors. The program will be rerun in 2009. Positive Life also provided training for positive people to engage with media, aiming to increase capacity to provide positive speakers for a range of media interaction. A workshop was developed to improve the media skills and confidence of 10 positive people to undertake media interviews during the lead up to World Aids Day. Speakers were allocated to respond to media interview requests as issues arose. This process will be repeated and further developed.
4. **Access to mainstream services** - A key role of the project is to identify and act on barriers to services for people living with HIV. A functioning health care complaints process is vital. In 2008, Positive Life and HALC prepared a joint submission to the parliamentary Joint Standing Committee on the *Health Care Complaints Act 1991*, which identified significant shortcomings in the current scope and practice of the Health Care Complaints Commission: its unresponsiveness to non-prosecutable complaints; non-effective outcomes for complainants; and the fact that it is increasingly abandoned by people with HIV who are dissatisfied by the quality of health care provision. A copy of the submission was sent to the AIDS and Infectious Diseases Branch of NSW Health for further action. The enquiry has been delayed by the NSW Parliament till Nov 2009.

Positive Life is also focussed on improving HIV services to people in regional and rural NSW. Last year, Positive Life facilitated a workshop in the Hunter/New England region to identify access issues for clinical and support services. A report with recommendations was delivered, and discussions to address these issues are underway. Positive Life also undertook a trip to Albury with ACON, BGF, and PozHets, to meet with people living with HIV, supporters and local service providers. A report and evaluation are in process. Further trips to Queenbeyan and Bega are scheduled for May 2009.

5. **Improved S100 dispensing** – Data from the Sydney Gay Periodic Survey identified increasing proportions of people living with HIV are resuming full-time employment, so addressing difficulties of full time workers' collecting anti-retroviral medication is a priority. Positive Life has been negotiating with State Area Health Services with good results, however, the Commonwealth Department of Health and Ageing is reviewing the arrangements for **all** Highly Specialised Drugs, and HIV drugs are within this category. Some state health departments claim this may change the current situation for administration of scripts and dispensing of highly specialised drugs, as it will no longer be managed through the States, but through Medicare Australia, and they are yet to confirm their guidelines for how they want to manage all of this. When the changes are implemented we will find out if there are any significant changes, but our information is that the Commonwealth Pharmaceutical Benefits Branch is keen NOT to add more burden to the prescribers or patients.

New work 09/10

A new program will be developed to provide guidance on how to use the health care system, what you should expect in terms of quality of care, and what to do when it goes wrong. A forum for employers is planned on employees with HIV, to inform future work to improve working conditions for positive people. Positive Life will continue to build regional networks and identify opportunities to engage regional people with HIV and service providers (prioritising the southern and western regions of NSW). We will provide ongoing media training and aim to better use positive speakers. Two planned areas of major areas of work relate to: 1. mental health: scoping exercise to investigate support needs, service research and to develop an advocacy strategy for mental health; and 2. Insurance: scoping issues, ensuring actuaries are working with current information, and develop advocacy objectives and strategy.

5. ASHM/NAPWA Models of Care

Stephanie McLean: Senior Project Officer, ASHM

The Models of Access and Clinical Service Delivery for HIV-positive People in Australia project started in July 2008 as a partnership between ASHM and NAPWA, with an additional paper commissioned by ARCHRS. The project was overseen by the BBVSS and the MCBVSS. There was an advisory panel made up of government and NGO representatives, with a steering committee including ASHM and NAPWA representatives.

The project found that:

- the client group is changing - there are increasing numbers of new cases, and increasing life expectancy with people aging
- the clinical response is changing - increased complexity of drugs, side effects, increasing outpatient care, HIV being seen as a chronic disease, comorbidities and social and psychological factors that at times took precedence over the medical issues.
- the workforce is changing - an aging workforce with issues around recruitment and retention, replacement and training practices
- the health systems are tailored to addressing acute and hospital based care, not outpatient or long term, chronic care
- there are a number of policy changes occurring
- the global financial crisis is an unknown quantity
- data assumptions and projections remain problematic as there are still gaps in data

The process included literature reviews, questionnaires and interviews with key stakeholders, data collection. Some information was very localised, state or community based and possibly generalised, problematising the evidence base. Six background papers and a summary were written (full details are available in those reports at <http://www.napwa.org.au/search/node/models+of+care>):

- HIV populations in Australia
- Existing HIV clinical services and HIV populations
- International approaches to access and delivery of clinical services for PLHIV
- Models of access and clinical service delivery for people with HIV used in Australia
- Models of care for chronic disease
- Australia's Health Workforce: roles, supply, trends, recruitment and capacity to deliver HIV services
- Models of Access and Clinical Service Delivery for HIV Positive People in Australia - Final report

In February, the Advisory Panel reviewed all papers and developed a number of demonstration projects which include:

- Shared Care – to increase the capacity of GPs to improve clinical outcomes of people living with HIV. It supports nurse practitioners and practice nurses, and partnerships between regional GPs and specialists.
- High Caseload S100 Prescribers – experiencing increased pressure. Need to consider the impact of pressure on small number of doctors.
- Nurse Based Initiatives – particularly relevant outside urban areas, including community based nurse models, nurse practitioners and practice nurses.

The project also produced recommendations around implementation and evaluation (building a stronger evidence base) and supporting enabling environments (linking this into other research and informing the National Strategy). The project should be understood as highlighting issues and raising further questions for strategic, coordinated action.

6. Centrelink Issues

Linda Forbes: Casework Coordinator, Welfare Rights Centre

From 1st of July this year, same sex relationships will be recognised under Social Security law. We use the terminology 'recognition of same sex relationships' because that is what Centrelink will use, and what is used in the impending legislation. Recognition of same sex relationships is supposed to be all about equality and equal rights for people in lesbian and gay relationships. Our problem with the legislation is that there are no savings provisions. So from the 1st of July anyone living with another person in a de facto relationship, whatever that may mean to people in gay and lesbian relationships, will be considered to be in a de facto relationship, and assessment of their social security and family assistance entitlements will change.

The worst case scenario will probably apply to someone who has been in a long term relationship, or is entering into a new relationship just now, sometime before the 1st of July. We are most concerned about people who have been on pension for a long time. If a person has a partner with fairly significant income and/or assets they may well lose their pension from the 1st of July. If there had been savings provisions (or 'grandfathering' provisions), such people would retain their pension and Centrelink recognition of same-sex relationships would have been cause for celebration, as for other same sex right reforms. But many people who advocated for equality for gay and lesbian people for decades are now left with none of the benefits of the law reforms. The 'reforms' just mean losing their pensions.

Welfare Rights is a community legal centre which provides expert legal advice and advocacy for people with adverse social security or family assistance decisions made by Centrelink. Centre staff give advice or assist people through the appeal systems if, for example, Centrelink has reduced someone's rate of pension, taken their pension away, rejected a claim for pension, or imposed a penalty (for example, because they are on a Newstart or Youth Allowance and not coping with activity requirements).

Our perspective on same-sex relationship recognition comes from our long experience assisting people alleged to be in marriage-like relationships. The concept of marriage-like relationship is a can of worms - as is the concept of a de facto relationship. You can decide to move in with someone and have a sexual relationship, but may just be flatmates. You may well only think that you are going to stay together for three weeks, or six months, or a year, and have no plans for the future - no concept of de facto marriage. Marriage may be something you're opposed to. I have spoken to many gay and lesbian people who are horrified they have been caught in this mainstream notion of de facto marriage. Gay and lesbian people in gay and lesbian relationships can't marry, so it is all a bit rude. The concept of 'de facto' may very different for a gay or lesbian person than for a straight person who has lived in a society that has accepted the concept well and truly since the 1960's. The concept of gay and lesbian de facto marriage is difficult for many people in gay and lesbian communities to wholeheartedly embrace, and not everyone wants gay marriage.

From 1st of July, it will be a whole new ball game. Despite our battles, the government insists that 'same is the same': 'if people want equal rights it is all going to be equal', so all same sex law reform, including Social Security, will come in at the same time. We must help people decide whether they need to come forward to Centrelink and if what will happen if they do come forward.

Some will be impacted by a new assessment that they are a member of a couple. For people on Disability Support Pension, it will mean that the combined partnered income and assets tests will affect the rate of pension. So, at the moment, if you are on Disability Support Pension, and you live with a partner who earns \$100,000 a year, or you live with a partner that has an investment property, you get single rate of Disability Support Pension with no assessment of your partner's income and assets. From 1st of July, if you come forward as being a member of a same-sex couple, your rate of pension will be reduced, taking into account half of your partner's income and assets.

In some instances, individuals will be better off, for example, if the combination of a couple's assets means the partner is also entitled to a small pension because the income and assets are spread across the two partners. However, what we are concerned about is people who will be worse off: particularly those who suddenly have the rug pulled away - suddenly lose pension, particularly older people who have planned retirement on the basis of financial independence, who now will be forced into financial interdependence. We are also concerned for young people who will suddenly be

required to tell Centrelink about a same-sex relationship that they have entered into. We are aware of very young people coming to Sydney from regional areas of NSW because of their sexuality, because they can't cope in their local community. Their relationship with their family may have broken down. Suddenly, having to front up to Centrelink is very confronting.

We believe there is some room for movement when looking at what Centrelink must take into account when considering whether someone is in a de facto relationship. Centrelink will say that the de facto assessment is the same for opposite and same-sex couples, but it should not be the same because relationships are not necessarily the same.

When assessing whether or not a person is in a de facto relationship, Centrelink must consider certain factors, which are set out in the legislation. From 1 July, the same factors apply to everyone. They cover financial arrangements, accommodation and domestic arrangements, social relationships, sexual relationships, relationships with children, and commitment to each other. All these factors have to be weighed up. It's not like one, two, three, tick-a-box.

- **Financial arrangements** are crucial. I have some concern that a lot of people I have been talking to are talking about 'covering their tracks', concerned that maybe they made out their will leaving everything to their same sex partner and described that person as a partner in the will, or are concerned they have entered into a loan describing the other person as their partner to a financial institution. Or they might have a joint account. I would advise people to be really careful in considering whether to cover your tracks, because Centrelink's investigations of marriage-like relationships can go back years to prove that someone has been in a marriage-like relationship. Clearly going into detail on these issues is difficult, and for service providers assisting their clients, it can be really nosy-parker, confidential, horrible stuff. However, often it is the details that will show whether or not a relationship may be defined as de facto.
- **Accommodation and domestic relationships** – can be considered from different perspectives. For example, if you share all the bills, what does that mean? If a person and their partner have an arrangement where one pays for the electricity while the other pays the gas bill, what does that mean? If one person pays all the utilities and the other one pays the rent, what does that mean? If there is a reason why things are worked out in a particular way, explain that to Centrelink.
- **Social relationship** - is important. If a person says they haven't come out fully to family and friends regarding their sexuality, that is one thing. If they haven't come out to family and friends as being in a kind of de facto close relationship, that is another. Explain this to Centrelink. Most of the people that I have spoken with and have given advice to have ended up in tears because they are so worried about engaging with Centrelink. Mature and older gay men and lesbians compare the experience of disclosing relationship details to Centrelink, to coming out to their parents – long ago.
- **Sexual relationship** – is not decisive but is very important. If you are in a sexual relationship with a person you share with who you would describe as your boyfriend or girlfriend, Centrelink will jump to the conclusion that it is a de facto relationship, particularly with young people. If you don't agree with that assessment, it will be important to provide further details on the other aspects of your relationship, or your attitude to what a sexual relationship 'means'.
- **Relationship with children** – can be difficult to describe, and if children are involved, it may be best to seek assistance from Welfare Rights Centre.
- **Commitment** – is an important criteria, however, it is also important to note that commitment can change over the years. It could be that you were previously in a relationship and that if the law had changed some time ago, it may have become a de facto relationship, but people stay together for different reasons, including companionship or care, which may be particularly relevant if a partner has HIV.

Essentially, if you have clients who are concerned about the changes to Social Security, I encourage you to refer them to Welfare Rights Centre. We also have a fact sheet on our website that is particularly designed to address the concerns

of gay and lesbian communities. We are putting a lot of effort into working with people through this change, and largely advise people that if they think they might be in a de facto relationship, they should declare because the consequences of not declaring can be significant, including the accumulation of a large debt. If you are assessed as being in a de facto relationship and don't agree with that assessment, it is simple to appeal – a process with which Welfare Rights Centre can assist.

7. The Tooth Fairy - EPC Medicare Dental Scheme Update

Lance Feeney: Positive Life

The Enhanced Primary Care (EPC) Medical Dental Scheme was introduced by the Howard government in Nov 2006. The scheme provides \$4,250 of Medicare rebated dental services over two calendar years. GP's can refer a patient with a chronic condition to a private dentist if they believe the patient's oral health is impacting on, or likely to impacting on, their general health.

The Commonwealth Dental Health Program (CDHP) was announced by the Labour government when it came to office to reduce waiting lists for public dental service patients (\$290 million over three years). Health Minister Roxon has repeatedly stated that the CDHP and the EPC scheme cannot coexist. The government has unsuccessfully tried twice to have the scheme abolished in the Senate, with the Coalition, Greens and Independents blocking. NSW currently spends the lowest per capita amount on public state funded dental services

In November 2008, Association for the Promotion of Oral Health (APOH) research of Medicare statistics revealed a generally balanced use of Medicare funds. Some regulation of Crown and Bridgework was recommended to prevent over-servicing (recently identified in relation to crowns, bridge work and implants). Also, there are massive disparities in take-up of the scheme across the states and territories. There has been little promotion of the scheme except in NSW.

The repeated claims that the government's alternative CDHP would be fairer than the EPC Scheme are unjustified and demonstrably incorrect (based on APOH analysis of data). The case for discontinuing the current scheme does not stand critical analysis. The Australian Dental Association and others have repeatedly asked for tighter patient access criteria and tighter access to specific services. Medicare and the Department of Health and Ageing have not responded to these concerns.

The Government needs a solution to the impasse and is talking to the Coalition, Independents and Greens about a compromise. The Coalition does not want to be seen to support a scheme where there is inappropriate servicing/rorting.

Finally, there remain problems with resources/capacity, with only 10% of dentist working in the public system - providing 50% of total dental services in NSW.

8. Immigration Issues

Brady: HIV/AIDS Legal Centre

The visa categories for which a health waiver is currently available are basically the partner and family formation visas: so partner, interdependent spouse, de facto spouse, fiancé, and some of the child visas, and I think the parent visas. The other visa category for which there is a health wavier and which has operated for a number of years, is the 457 visa which is the temporary work visa. Ordinarily, it is a four year visa. For 457 visas, the health waiver requires an undertaking from the nominating sponsoring employer of the applicant, that the employer will pay the health costs of the employee if and when that migration applicant incurs them.

The health waiver in all other circumstances pretty much operates the same way, and that is that it is a balancing of the significant cost of the health and medical condition that the applicant has, versus all the other circumstances in the matter, and whether or not that significant cost that the applicant represents to the Australian community in terms of health care and services provision, is undue in all the circumstances. So it is not rocket science. It is a pretty straight

forward test. Historically it was a very hard test to meet and ordinarily, prior to about 2005, applicants would expect to be refused by the delegate at the initial application stage and have to go through to the Migration Review Tribunal before they could possibly get a positive outcome. But for approximately the past three years, people have been more routinely able to get the health waiver from the delegate, that is, at the initial visa application.

In relation to Immigration, I suppose I have a good story to tell. There have been some positive movements that came through just in March, and there are future positive movements from this Government in relation to broadening the availability of the health waiver in skilled visa categories. Currently it is in the employer nominated scheme only available in Victoria and the ACT. The Federal Government, as we understand it, is hopeful that other states will get onboard and sign up to this scheme allowing the health waiver for skilled visa applicants - Employer Nominated. The second positive note is that the Federal Government is undertaking a review of the health criteria of the *Migration Act*, and that terms of reference have begun to be promulgated or are promulgated. I've been talking with some people in relation to establishing some sort of working group to try and get the HIV sector's position clarified in relation to that Federal Government review.

To talk about specifics in Migration: there are health criteria applicable to all visa's but there health waivers are only available with some Visa categories. Anyone with HIV will require a health waiver: a waiver of the health criteria.

9. National HIV/AIDS Strategy

Don Baxter: Chief Executive Officer, AFAO

The National HIV/AIDS Strategy will shortly be reviewed and rewritten. There will actually be at least four strategies: HIV, STI, Indigenous Sexual Health and Hep C. There may also be a Hep B strategy.

The Strategies will not be contracted out but will be written by a small team from the sector. For each strategy, there will be a team of two writers and a small reference group of 6 to 8 people. Those reference groups will be appointed by MCBVSS following nominations. There must be two people under 30, and at least one general practitioner on each reference group.

The notional timeline (not yet approved by the Ministerial Advisory Committee) aims for approval by the Health Ministers' Council Meeting in November '09. We hope writers will be contracted and groups established by end June, with a template distributed mid July. We believe we can expect first drafts to be available in early August, with a 6 week consultation period. The only opportunity for national consultation will occur at the conclusion of the ASHM conference. Final drafting is to be done by late September.

Participants then broke into small groups to discuss ideas for inclusion in the National HIV/AIDS Strategy.

Issues to be addressed in the National HIV/AIDS Strategy
<i>Feedback from small group discussions (not consensus decisions of the Forum)</i>
Stigma and discrimination
Mental health
Repealing criminal laws
Advocacy as a stand-alone policy
Models of peer support having a higher profile, and including sero-negative partners and friends
S100 access, dispensing and new drugs, and GP's S100 training including a community organisations component
National education for mainstream sectors

Before accepting mainstreaming, need to accept suitability to specific needs of our clients
Partnerships with agencies: drug and alcohol, mental health, Heart Foundation, Cancer Council, NGOs working in other communities
Greater coordination between Commonwealth and state HIV efforts to achieve better pathways to effective mental health care
Training PLHIV – funding and infrastructure to support the movement of PLHIV (eg. university)
Aging and aged care, HIV and premature aging including mental health, expanding definition of aged care, training of aged care staff on HIV and chronic illness and same sex relationships
Valuing positive communities (not just clients), community re-engagement
Describing components of models of care including workforce issues
Rural/regional clinical management models/shared care
Evaluation mechanism built into timelines of implementation, with ongoing monitoring
Evidence based decisions to determine priorities during the life of the strategy
A whole of government approach
Social inclusion/social determinants of health to be included
Balance tension between infected and affected communities
Identify priorities re: comorbidities
Harm minimisation, stigma and discrimination
Effectively implement national guidelines on persons who place others at risk of HIV infection
Biomedical intervention
Better referral pathways
Social isolation
Oral health/dental, dental care scheme to people with chronic illness, use of private practitioners with incentives for their involvement
Continuum of appropriate housing models
Carer needs
HIV and sexual health planning
Outpatient clinics for PLHIV who work
Government backed insurance inclusive of PLHIV
Control over E-health records
Support for self management and self monitoring
Sex workers living with HIV falling through service delivery gaps
Leadership around importation of HIV drugs
Safety net for Medicare ineligible
Women
Role of social determinants of health in national strategy
Ensure care and support extends beyond clinical

Peer support is vital
Highlight diversity of PLHIV
Community pharmacies
Keep HIV and HCV strategies separate

Mental Health and HIV

10. Understanding and Managing Mental Health

Jodie Butler: Clinical Psychologist, H2M Service, St Vincents Hospital

In understanding mental health, it is important to start with the idea that all behaviours and feelings occur on a spectrum from what can be termed 'normal' to 'clinical'. 'Clinical' occurs when there is significant distress or impairment of functioning, which may be social, occupational, or may occur in other important areas. Also, when working with a person on a particular issue, it is important to rule out other mental health conditions, medical conditions, drug or medication effects.

Depression and Dysthymia can manifest through a range of symptoms including those that are:

❖ Physical

- Change in sleep pattern
- Change in eating pattern
- Fatigue
- Loss of energy
- Body aches and pains (somatic)

❖ Behavioural

- Loss of interest in pastimes/pleasure
- Difficulty concentrating
- Difficulty making decisions
- Neglecting responsibilities
- Neglecting looking after yourself
- Slowed movements

❖ Emotional

- Inappropriate guilt
- Crying
- Feeling 'down', apathetic, irritable, pessimistic, negative, 'black'
- Thinking negatively about oneself
- Feeling hopeless/helpless/worthless
- Feeling suicidal or having recurrent thoughts of death

It is important to remember that everyone has down days, so a person feeling sad or depressed on a given day may not be experiencing something that would clinically be defined as depression.

If you believe a client is depressed, there are a range of things you can do and recommend:

- Encourage ... Encourage ... Encourage
 - exercise
 - decrease in alcohol, substances
 - balanced diet
 - time in the sun if appropriate
 - decrease in caffeine
 - access to support networks
- Label emotions
- Listen
- Use problem solving skills
- Do relaxation exercises
- Set boundaries, routine & structure
- Any activity is helpful
- Adherence to medications
- Refocus on valued areas of life (including links to exercise)
- GP or specialist referral

If a person is so disconnected from life that they are not engaging at all, look at what is going on at home that they can re-engage with. It may be as small or big as where they are 'at: 'meet them where they are'. For example, consider self care, or if they used to watch dvds – reengaging interest. It is important to begin momentum, eg. from having a shower each day, then focus on moving further.

1. Anxiety

There are a variety of anxiety disorders including social (eg. public speaking) and specific phobias (eg. spiders, heights, elevators). Anxiety is about:

- persistent and excessive fear
- exposure to feared object/situation provokes immediate response
- avoidance

❖ Panic

Can be a difficult cycle to break, because the more you panic the more you panic until you're panicking about panicking. It is useful to understand that your heart racing is a physical response to panic (eg. not a heart attack)

- physical sensations are related to adrenaline – 'fight or flight' response
 - Breathing increases
 - Heart rate increases
 - Dizzy, tingling sensations (non-essential systems shut down)
 - Nausea, sweaty or clammy (non-essential systems shut down)
- fear of losing control/dying

❖ Generalised anxiety

Problematic anxiety is excessive worry about a variety of topics (usually five or more things) all the time so that it is difficult to control worry

- physical symptoms
 - Restless
 - Irritable
 - Tense
 - Sleep disturbed, tired

- Poor concentration (because so many things running around in mind no room for anything else)

❖ 5. **Obsessive Compulsive Disorder**

Obsessive compulsive disorders involve disturbing, intrusive, inappropriate thoughts, images, impulses and:

- attempts to ignore, neutralise or suppress
- repetitive behaviours or mental rituals to neutralise obsessions

❖ 6. **Acute and Post Traumatic Stress**

Acute and post traumatic stress is usually triggered by a traumatic event where:

- response involved fear, helplessness, horror
- the event is re-experienced by recollection, dreams, reliving, flashbacks
- there is avoidance of things associated with trauma (thoughts, places, people, memory, detachment)
- there is increased arousal (sleep, anger, concentration, hypervigilance, startles easily)

What you can do

- Don't enable avoidance - anxiety is decreased when the thing is avoided but that cuts off parts of life, and may trigger isolation and depression
- Don't panic with panic
- Tell them 'It's ok to be anxious' – it's normal and we all have it
- Be patient
- Ask 'what is the threat'
- Don't fight the panic
- Don't say 'don't be anxious'
- Assist them to stay in the present because anxiety is about the future, i.e. what might happen
- Concentrate on a simple task
- Try to undertake relaxation
- Label emotions, sensations

Psychosis

Psychosis describes an inability to distinguish what is real — there is a loss of contact with reality

- *Confused thinking* - disordered thinking, confused, disjointed, paranoid
- *Delusions* - false belief, which is not held by others of the same cultural background
- *Hallucinations* – seeing, hearing, feeling, smelling or tasting something that is not actually there

What you can do

- Ensure safety of all
- Don't agree with them
- Acknowledge that is how they see the world
- Move to a less stimulating environment
- Refer to GP or local community mental health

Mindful of Yourself – It is easy enough to be sucked into the 'not that client again' or 'what are they coming in with today?'. Workers must be in the present. Do an exercise – notice three things you can see right now; three things you can hear right now; three things you can feel on your skin. That exercise can bring you into the present.

General Drug Use

You may recommend:

- Minimal to no drug use
- Exercise
- Balanced diet
- Sleep
- Regular social interactions
- Regular meaningful activities
- Say Yes!!!
- The matter test

Know Your Local Resources

- Community Mental Health Team
- Local GP's
- HIV specific services
- Lifeline - 131 114
- GLBT Counselling Line - 1800 184 527
- Mensline - 1300 78 99 78
- www.blackdoginstitute.org.au
- www.crufad.org
- www.sane.org
- moodgym.anu.edu.au
- www.glccs.org.au

11. Community-based Mental Health Services Working with Positive People

Malcolm Scott: Northern NSW Regional Manager, NEAMI

Neami is a national, non government, psychosocial health and rehabilitation support provider that works with and on behalf of people with a mental illness. Neami works to identify service gaps in the community, to develop new services, and to achieve community acceptance, protection and expression of the rights of people with psychiatric disabilities in the community. It aims to influence service systems so that people with a mental illness are socially included in Australian society. Neami receives national and state funding. It began in Victoria as de-institutionalisation was rolled out, assisting many from long term psychiatric care back into the community.

Neami's Board of Directors includes consumers who have previously accessed services, and consumers, staff and committee have defined the values that drive Neami's recovery vision. These values are:

- Self determination
- Hope
- Change
- Respect
- Growth
- Choice
- Empowerment
- Wellbeing
- Learning

- Partnerships
- Acceptance of diversity
- Quality

Neami believes better outcomes for consumers are achieved by:

- Assisting consumers to build their resilience and strength to make their own choices about their own recovery
- Working with consumers to build their confidence while participating in their community of choice
- Assisting consumers to plan their own program and build their connections with their community
- Assisting consumers to develop the skills and competence necessary to enjoy a full and rich quality of life

Neami's supported housing provides safe, secure and affordable long-term housing coupled with support to people who experience mental illness. The housing support service is predominantly provided to the 16 to 64 year old age cohort, with some services for those entering long-term aged care. Support is frequently provided in partnership with other providers, including supported accommodation providers.

Models of services are based on psychosocial rehabilitation – or goal based support: working to identify a person's needs, with regular (6 monthly) reviews, and working towards those goals.

Teams of staff (community rehab and support workers) work one on one through outreach. In NSW, they work predominantly with three area health services. Support is available from 'low' (up to 5 hours/week) to 'high' (8 hours/day) as it is required. (Often long term support not long term and often not conducive to recovery long term.)

Neami psychosocial rehabilitation programs are run in the local community allowing consumers to re/connect with their community, and providing community members with an avenue to address issues of stigma associated with mental illness.

Psychosocial programs at Neami provide some of the following benefits:

- Improvement in confidence and self-esteem
- Development of social networks
- Improved general health and fitness
- Development of living skills
- Opportunities to engage in study or return to work

NEAMI relies on specialist clinical service providers and others. Staff have experience working with specialist clinical support and HIV support, and work to avoid duplication.

Entry criteria is quite flexible. For high level support, some diagnosis is required but the main focus is on how a person's diagnosis is impacting day to day functioning. Neami has a 'no wrong door' policy so doesn't exclude people based on previous behaviour, and also works with those with substance abuse issues. The focus is on outcomes through a 'recovery based service', with 'recovery' defined by persons being assisted.

Outcomes under the Housing Assisted Support program have been impressive. The results of independent evaluation have been used to leverage further funding. Neami's key directions include the goal of influencing policy makers to develop a national framework, benchmarks and a standardised approach to mental health care. Neami is also pushing for the development of, and reliance on, a stronger evidence base.

12. ACON Mental Health Services

Russell Westacott: Director of Client Services, ACON

(Kerry Saloner: Manager, Counselling & Enhanced Care Services, ACON)

Following is a case study of how one NGO (ACON) works across HIV/AIDS-related services and Mental Health. ACON is a community-based, non-government organisation that promotes the health and wellbeing of NSW's GLBT community, and provides information and support to people living with or at risk of acquiring HIV.

ACON operates a state-wide service (NSW), which includes access for temporary residents/visitors to NSW. All ACON branches work collaboratively with local Area Health Services. There is close liaison with, and support to, ACON branch staff. ACON also provides telephone work with clients in other regional and rural areas – recognising that communities aren't just geographic.

The Counselling & Enhanced Care Services unit has three main areas of operation:

1. Counselling Project (9am-5pm)
 - Intake & Assessment
 - Brief Counselling
2. Volunteer Counselling Project (6pm-8.30pm)
 - After Hours Counselling
 - Therapeutic Groups, eg. anxiety, anger management, depression
3. Enhanced Primary Care Project
 - Taylor Square Private Clinic
 - Holdworth House
 - Working with 407 doctors

Clients are mostly from the LGBT community but also include those who interact with these communities, e.g. non-gay identifying MSM. Some 40% of ACON's clients are HIV positive, and ACON provides services for all people with HIV/AIDS: 15% are heterosexual (usually HIV+), about 20% CALD clients, with clients predominantly in the 30 – 39 years age group.

ACON's work relating to counselling relies on principles that include:

- Client-centred work
- Utilising an individualised approach
- Various approaches within the Humanistic and CBT models
- Eclectic models promote client autonomy based on client needs

Challenges remain around lack of evidence with regards to some issues e.g. complexities of same sex domestic violence, homophobia and grief work. The counselling service also provides support on existential issues, for example, ageing.

Health Promotion	Early Intervention	Diagnosis	Treatment	Rehab and Palliation
Counselling and Enhanced Care Span the Spectrum				
Provision of support; psycho-education; prevention info.	Work with vulnerable/at risk clients	Prompt confidential support to reduce impact of a diagnosis as a potential traumatic event	Support through transitions; care co-ordination	Counselling and support for life change; grief and loss issues

Clients that present might be positioned:

- ❖ Anywhere in the HIV/AIDS spectrum

HIV negative	At risk	Newly diagnosed	Living long-term with HIV	HIV progressing and unwell
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- ❖ Anywhere in the mental health spectrum

Functional	Situational distress affecting mental health	Recent traumatic event leading to acute stress	PTSD and other longer-term/ chronic stress	Chronic mental illness; Psychosis
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- ❖ And there is often an overlap between HIV/AIDS and mental health issues, as issues from both spectrums may overlap at any point.

ACON has a dedicated intake and assessment position, which ensures counsellors are free to conduct counselling. From July 2008 to early June 2009:

- 134 clients presented 'in crisis'
- 84 with HIV-related issues (not necessarily HIV+)
- 154 with mental health-related issues

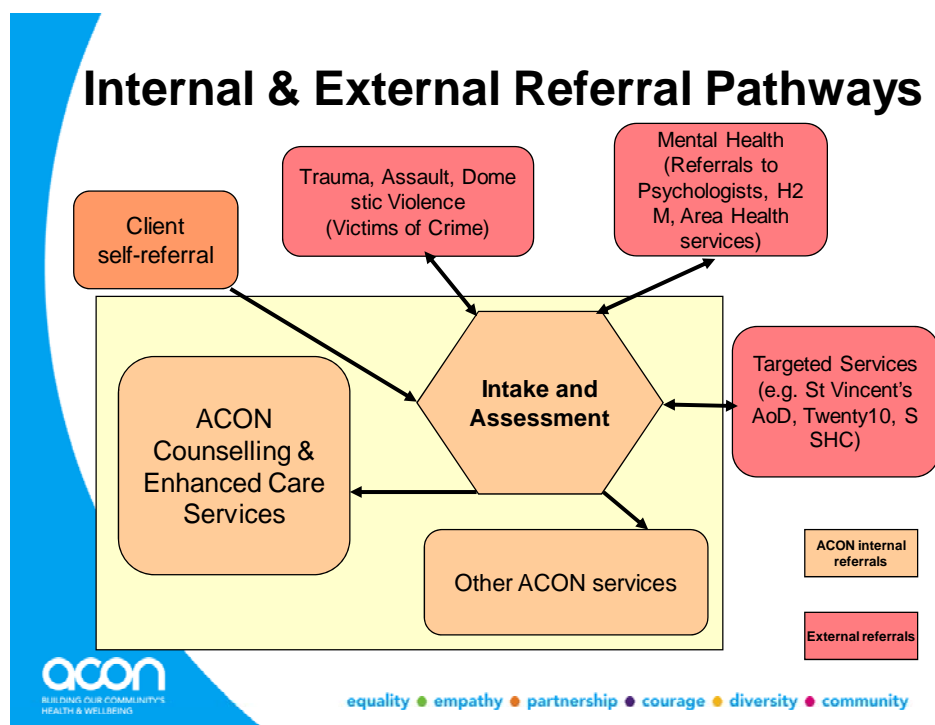
Other presenting issues include same sex domestic violence, relationship issues/ couple counselling, alcohol or other drug issues, violence, sexuality, financial/unemployment, socio-legal issues.

Mental health related work

- Situational

- Team's role varies:
 - psycho-social assessment
 - mobilising support
 - referring out to more relevant organisation
 - or provide support working collaboratively with other services
- Individual follow-up is provided to clients who are referred out

The following gives a graphic idea of the referral process and who ACON works with, with intake and assessment the first port of call. ACON does refer out, recognising that it is not always able to provide the most appropriate service.



ACON aspires to:

- contribute a unique and vital role
 - be integrated in the landscape of services
 - complement a range of existing services
 - constantly work with other services
 - work on a mutual referral basis – refer on and expect referrals in
- ACON recognizes that *best practice* involves collaborative approaches.

In this year, July 2008 – present (early June 2009):

- The daytime counselling team provided 4000+ occasions of service (15 minutes or more)
- Volunteer counsellors provided 1152 counselling sessions during the evening service
- 8 therapeutic groups have been run
- The Enhanced Primary Care project is continuing in three high HIV caseload GP practices
- ACON is currently developing a Mental Health Promotion Strategy for release - year commencing July 09

All work in the Unit is governed by:

- Code of ethics of relevant professional bodies
- ACON ‘Code of Conduct’
- Internal Policies and Procedures
- Organisational Strategic Plan
- Annual Business Plans

ACON’s Commitment and Support includes:

- external, fortnightly clinical supervision for all staff
- onsite debriefing and support for all staff
- clinical supervision from external practitioners for all volunteer counsellors and group facilitators
- ongoing learning and development encouraged for all staff and volunteers

ACON continues to be a ‘port of call’ to members of our community because it:

- has a symbolic, long-standing and well-connected identity within our community
- is perceived as a sanctuary or safe space
- fosters an atmosphere of client self-determination
- offers an environment that ensures all our clients – and would-be clients – have a sense of belonging

13. Mental Health Training for Community Workers

Simone Montgomery: Learning and Development Unit, Mental Health Care Connect

Mental Health Care Connect (MHCC) is the peak body for non-government mental health organisations, with a membership of 200 diverse members (from one worker to large organisations). It has been around for approximately 27 years. MHCC fulfils a role as the peak body in relation to leadership, policy advice and advocacy, and does a lot of work with government to fulfil the role of a link between our member organisations and government.

The Learning and Development Unit is a relatively new addition, providing training to staff in the community mental health sector. During the last five to 10 years community mental health has ‘blossomed’ which is positive in that there’s now acknowledgement of the need and the need to take action. The workforce has expanded some 300% in the last three to five years, and of course those workers need to be trained.

MHCC offers nationally accredited training: short courses, specialised courses, customised courses for specific organisations, and management training. Accreditation includes a Certificate IV in Mental Health and Certificate IV in Drugs and Alcohol, acknowledging that many clients arrive with more than one issue/problem. (We believe the sector is still lacking holistic mental health services.) MHCC also offers a course based around the notion of emotional intelligence.

The new program currently being out is Mental Health Connect: a mental health course for community workers. It is now in its third pilot phase. The course was developed after Mental Health First Aid course, which is based on triage and increasing people’s mental health literacy, identified a broader need. There are many workers faced with clients with complex needs including mental health as an underlying presentation. People need to know, for example, if a client is having an episode – what to do. People are working with clients on an ongoing basis without the support of a mental health professional.

The program offers increased skills, recognition of mental health problems and appropriate referrals. The purpose is not to diagnose but to focus on the behaviour (rather than the illness), and work with that. Part of

the program also looks at the principles of recovery oriented issues. There is also a broader workforce issue – we need a skilled mental health workforce.

The community based mental health sector is quite unique in terms of the focus on empowering the consumer and consumer participation – rather than a client receiving a service. We look at principles of recovery, dignity of risk, legislation and various mental illnesses. We also look at skill development – tools you can use to work with your client. A lot of people already use motivational interviewing but are able to use it in another context. Dignity of risk is an interesting concept in that it balances with the notion of ‘duty of care’: It argues that people have the right to make choices, make decisions and take risks during their recovery process. That may result in the risk ‘working’ or ‘not working’ but people should not be denied that choice. It’s a rethinking of the notion that the consumer should be able to make an informed choice and to learn vicariously.

The strongest thing coming through from the training is that people are really skilled but have a low level of confidence in these settings. If people can leave the program more confident - that’s a success.

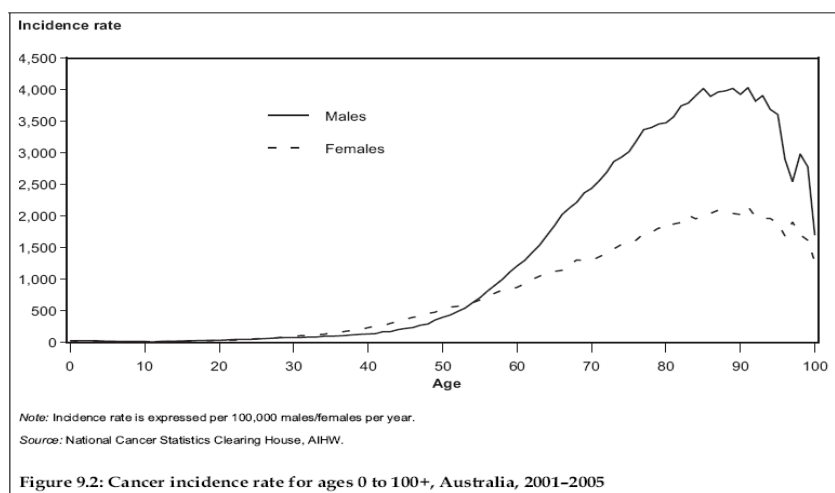
Ageing and HIV

14. Cancer in Ageing People with HIV

Andrew Grulich: NCHECR

When discussing the health of aged people, cancer is very relevant as it is strongly related to age. Prior to 50, it is a relatively uncommon disease but there is an enormously rapid increase in rates of cancer after that age. 50 is also round about the average age of people living with HIV, so that population is just about to move into the age where there is an exponential increase in cancer rates.

Another feature, demonstrated in the following graph, is that increases in cancer rates are not inevitable. The difference in cancer rates between men and women is almost entirely linked to the smoking rates of men and women 30 years ago. As smoking decreases, the rates of cancer among men will decrease.



In terms of the burden of cancer as a health related issue, cancer has the greatest burden in terms of years of life lost, ahead of cardiovascular diseases, mental disorders, neurological and sense disorders, chronic respiratory disease, injuries, diabetes, etc. The spread of cancers differs across sex:

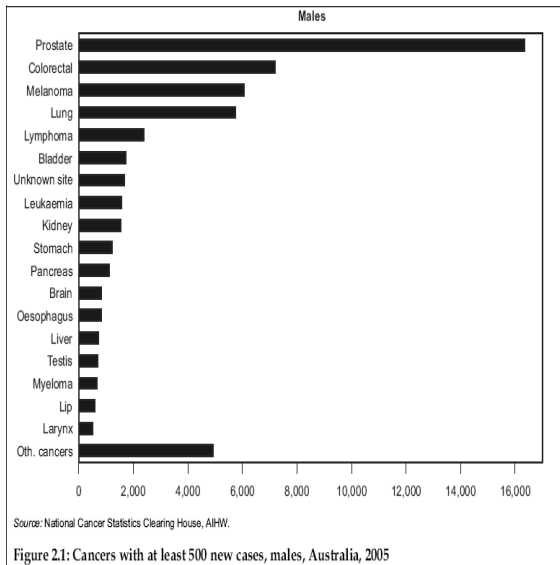


Figure 2.1: Cancers with at least 500 new cases, males, Australia, 2005

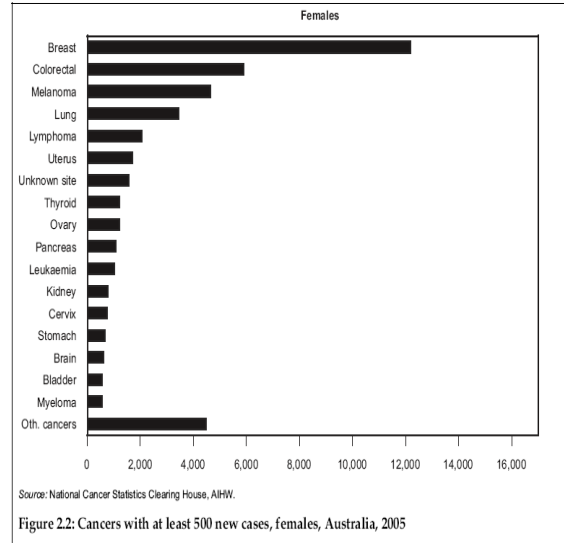


Figure 2.2: Cancers with at least 500 new cases, females, Australia, 2005

Cancer in people with HIV – 2000 to 2004 - The most common cancers in people living with HIV are non Hodgkin lymphoma, Kaposi sarcoma, anal, melanoma, lung, Hodgkin lymphoma, leukaemia, colorectal and prostate. Notably, anal cancer is the third most common form of cancer among people living with HIV and also very common among gay men although very rare in the non gay population. Anal cancer is slightly higher among women in the general population – 2 per 100,000/year but 40 per 100,000/year in gay men.

Preventing Immune Deficiency - Infection is the major cause of cancer in HIV positive people so immunodeficiency is responsible for a lot of cancers. The following slides explain a number of the infective agents linked to cancers. The more common cancers are caused by viruses. The big emerging issue is human papilloma virus (which also causes cervical virus in women), which is responsible for anal cancers in gay men.

As these cancers are related to infection there is some correlation to the type of infections people used to get in the days before HAART, however, unfortunately these are not as closely related as might be hoped, so the HAART drugs do not prevent all these infections/cancers. We are currently looking at CD4 cell counts in terms of cancer risk.

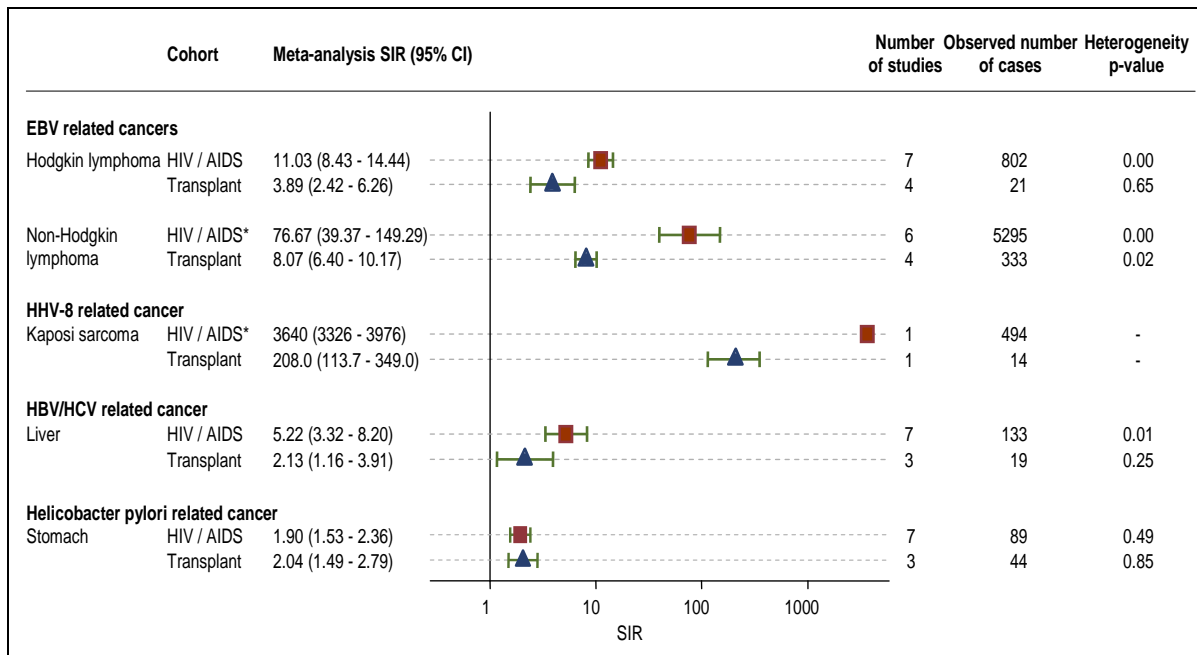


Figure 2: Standardised incidence ratios for cancers related to infection with Epstein-Barr virus, human herpesvirus 8, hepatitis B and C virus, and *Helicobacter pylori* in people with HIV/AIDS and in transplant recipients

EBV=Epstein-Barr virus. HBV=hepatitis B virus. HCV=hepatitis C virus. HHV8=human herpesvirus8. *For AIDS-defining cancers, data from cohorts defined by an AIDS diagnosis included only those individuals who did not have that type of cancer at the time of AIDS.

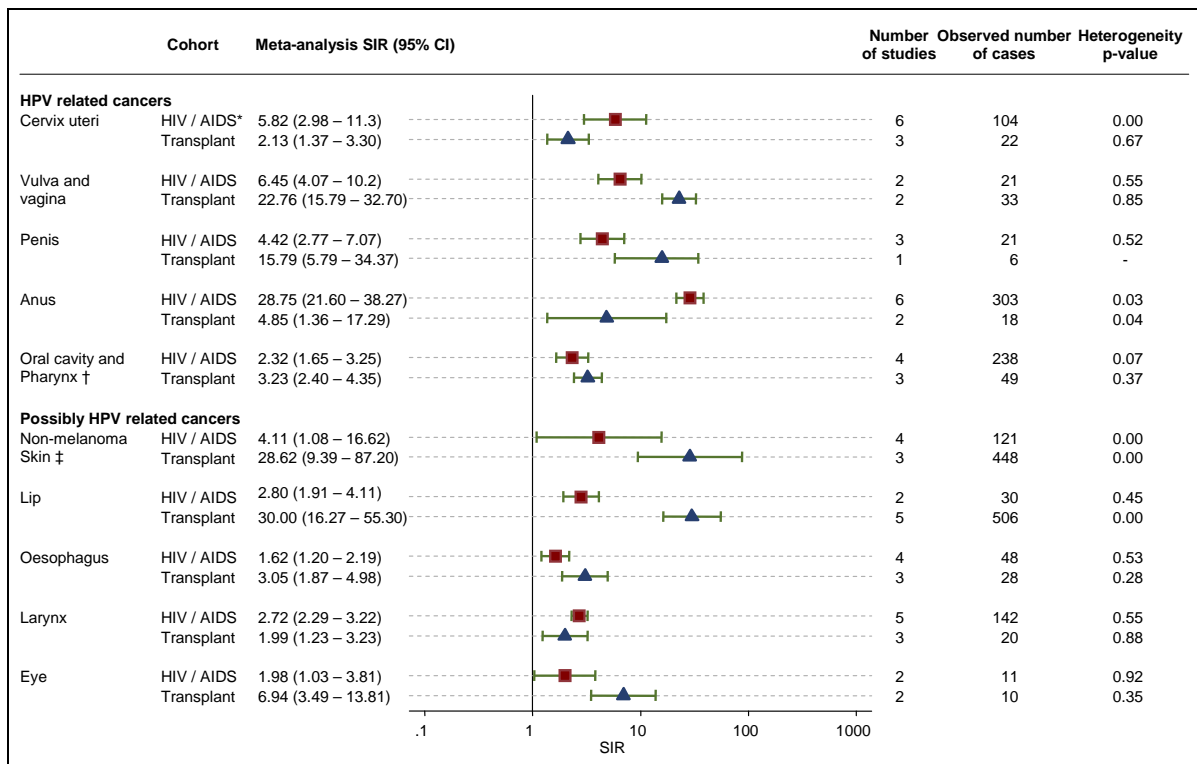


Figure 3: Standardised incidence ratios for cancers related to, or possibly related to, human papillomavirus infection, in people with HIV/AIDS and in transplant recipients

HPV=human papillomavirus. *For the AIDS-defining cancer (cervical cancer), data from cohorts defined by an AIDS diagnosis included only those individuals who did not have cervical cancer at the time of AIDS. †Excluding lip and nasopharynx. ‡Any measure of non-melanoma skin.

Immune function and cancer

A wide range of mainly infection-related cancer types is HIV-associated. Preventing immune deficiency will prevent much (or perhaps most?) HIV-associated cancer. The question remains, how high (in terms of CD4 cell count) do we need to aim? The answer is unknown, but will hopefully be answered by currently planned studies of early treatment of HIV infection.

Cancer and tobacco smoking

Tobacco smoking is central as a risk factor for cancer.

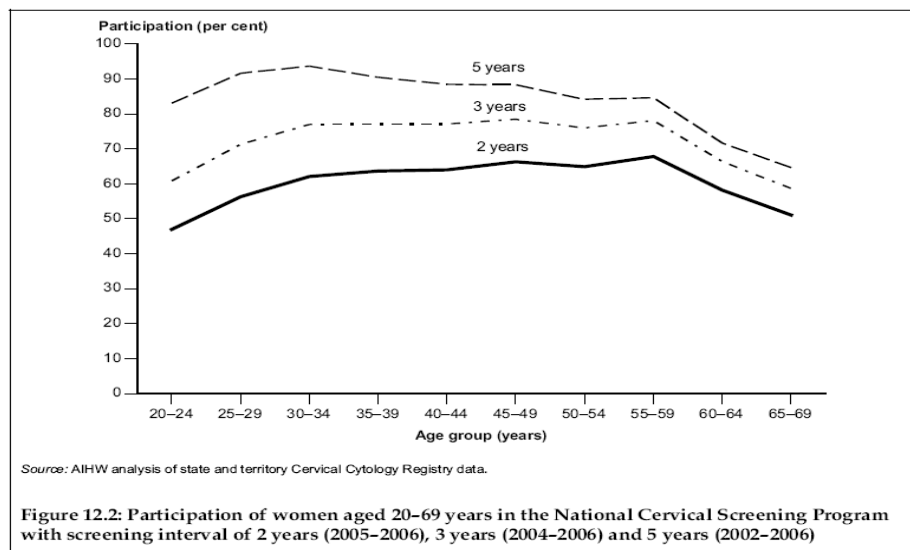
Table A.2: Cancer site and percentage of cancers attributed to smoking and excessive alcohol consumption

Cancer site	Males (per cent)	Females (per cent)
Cancers attributed to smoking		
Lung (C33–C34)	84	77
Larynx (C32)	73	66
Oral cancers (C01–C06, C09–C14)	57	51
Renal pelvis (C65)	55	48
Oesophagus (C15)	54	46
Anus (C21.0, C21.1)	48	41
Bladder (C67)	43	36
Kidney, except renal pelvis (C64)	28	21
Pancreas (C25)	24	19
Vulva unspecified (C51.9)	—	40
Penis (C60)	30	—
Stomach (C16)	14	11

People with HIV smoke much more than the general population: some 20% of the general population but almost half of positive people are currently smoking tobacco.

Early detection of cancer (screening) - Australia has national screening programs for breast and cervical cancer in women, and bowel cancer in men and women. Breast and bowel cancer are not infection related and don't differentially impact positive people. Prostate cancer testing does not appear to reduce mortality from cancer and doesn't appear at increased levels for positive people. Cervical cancer and bowel cancer, however, occur at markedly increased rates for people with HIV: cervical cancer is five times more common, and bowel cancer is 30 times more common. Cervical cancer screening among positive women (every year) appears to be working well. Screening participation decreases with age, which will be a challenge with an ageing HIV positive population.

Cervical Cancer Screening



Participation

Anal cancer screening is one of the most urgent research issues in HIV-related cancers. There is no accurate screening test. Anal pap tests have low specificity and sensitivity. Localised treatments tend to be painful and not very effective. The new vaccine for HPV introduced for young women (now almost universal) does not protect those already infected, and many gay men are already infected. We are not currently providing HPV vaccines for boys or young men.

Cancer will become a major HIV-related issue. The ageing of the HIV positive population means that cancer will soon become one of the biggest causes of morbidity and mortality in people with HIV. Cancer prevention is possible with:

- maintenance of optimal immune function (HIV treatment)
- smoking cessation
- cancer screening

Interventions of positive people should be the same as for the general population, except there should be increased frequency of cervical pap tests in women, and there is an urgent need for investigation of methods of prevention of anal cancer.

15. Overview of the Aged Care System

Ruth Wilson: Policy Advisor on Community Care, Aged Care and Community Services Association (NSW & ACT)

Aged Care Australia (ACA) is the peak body in NSW representing aged care bodies including not for profit, faith based organisations, and the profit part of the industry: some 300 member organisations. ACA does not receive funding from government: surviving on member fees, training, events, and the various other activities

ACA members provide services across the whole range of aged care: independent living units, residential aged care and community care. Some are large providers, like Catholic

Health Care and Uniting Care Baptist Care of NSW, but some are stand alone community organisations. The majority are based outside the metropolitan area, so our response to our members is about individual programs in local communities, which can be exciting: seeing some of the innovative work that is occurring from those local organisations responding to community needs. That localised response is important because the issues the aged care sector is facing are becoming so hard that centralisation into larger organisations is occurring, and those large organisations cannot do creative, responsive things arising from local need. Those marginalized in society may lose out.

The population is ageing, not just in Australia but worldwide. Life expectancy has increased enormously and many, many more are living well into their 80s. The birth rate has decreased and younger people are opting to have fewer children. So the ageing of the population is seen by many, especially the Treasury in government, as being the tsunami set to explode. The ageing population is seen as an enormous problem, while the contribution that ageing people are making and will continue to make is lost in that configuring. In NSW, 13% of the population is older than 65, which will rise to 17% by 2021. The fastest growing segment of the population is 85 plus, and we keep hearing stats about how many 100 year old plus people there will soon be around the world. There are higher proportions of older people in rural areas or coastal retirement areas outside Sydney. Men who are currently 65 are expected to live a further 16 years, and women another 20 years. Those are of course generalised averages, with major exceptions including the Aboriginal population.

The ageing demographic is taking place alongside major social change. Families are becoming more widely dispersed. There is an increased use of technology which keeps us alive longer. There are a lot of changes in work patterns. And there is a change in expectation about service delivery. Whether it is just the baby boomers or the generations coming after us, we are expecting a lot more for ourselves and for our parents as well, which is why Aged Care Australia is going through major change trying to respond to consumer demands.

Within the aged care sector you have got choices: to stay at home; to move into a smaller home; retirement village living whether it is lifestyle retirement or accommodation set up by a charitable organisations; and residential care – often referred to as ‘the end of the road’. Residential care is portrayed very negatively in the media; the place you go to when you are no longer a part of the community. I am waiting for the day when that distinction starts to fade: when people who need 24 hour care within a residential aged care facility are considered very much part of their wider community.

Fortunately in my role as Community Care Policy Advisor, I still have the freedom to be excited. I have some concern for my colleague who is a Residential Care Policy Advisor, as the policing by the Department is onerous: standards, spot checks, and new protocols every time something goes wrong. Residential care is a very highly regulated industry. The bad stories we hear are probably very much the exception to the good and creative work happening in residential care but those working in the area are locked into a very strongly regulated framework.

In community care we have a lot of freedom to look at how we work, and hopefully to influence government. Community care is the preferred option for many reasons; for those

needing care and, as the government is well aware - it is a much cheaper option than residential care. But we know there are limitations. If you require 24 hour care in your home, there are no government resources to make that happen.

Care is limited to government programs, and you may have heard yesterday from the Commonwealth government, that those programs are aged care packages: extended aged care at home packages, and extended aged care at home dementia packages. Under the Commonwealth program, theoretically people are not eligible to receive care at home until they are aged 65 or older. However, social workers often see younger people with early onset dementia or acquired brain injury, because there are very few residential care facilities for younger people - a State responsibility. In NSW, there are some 2000 people under the age of 65 in residential aged care. There is a proposal before COAG that there be a further division of responsibility for aged care.

As well as aged care programs, we have HACC: Home and Community Care. The Commonwealth provides 60% of HACC funding, and the States 40%, with the program managed by the States. HACC is broader than aged care, including younger people who require support in their own home. The fear is that the proposal before COAG will change that. The Commonwealth in the future will have the responsibility for all aged care and the States for people under 65, which is a cause of concern. AT ACS, we are beginning to identify those people who are going to be impacted by that division of the responsibility and to look at the quality of services that may arise if that division occurs. For example, what happens if I am getting a very intensive package of care by the State, and I then turn 65 and cannot be given the same amount of care under a different package. Am I going to end up in residential care? I would like to be treated as an individual, not as a person defined by a particular age.

NCOSS, along with ACS, have been endeavouring to really change the way we do community care: the growth area in aged care. We have potential to alter the philosophy of aged care. We have to report to our department that we have done so many showers, so many of this or that, to get our funding. Our challenge is to just get rid of that thinking. Let's get back to focusing on the person: me coming in to do my assessment as a supervisor and asking: What do you want to achieve in life? What are your goals? And let's see how we, with a flexible system, can start to respond to that. What do you really want? Do you want your cobwebs cleaned and your carpets cleaned next week, or would you rather me come with you and we hang out and do some shopping?

The five principles we are talking about in impacting HAC services, are that work should be:

- person-centred and that enables each consumer to explore individual strengths and goals, and work towards achieving the outcomes they desire with security and support for those who need it.
- culturally appropriate, socially inclusive, and sensitive to individual circumstances, social context and relationships, enabling the consumer to continue with what is important to them.
- flexible and responsive to the range of changing needs, interests and choice of consumers.

- supportive and enabling of positive relationships between consumers and their careers.
- recognized as the fundamental valued part of the society that grows and develops to meet the changing expectations of consumers, careers, funders and the workforce.

And this is the philosophy that is really driving us at the moment. It is about the people, our clients who we have as an absolute privilege to come along side - not to do for them, not to even use the word 'care' for them, but to enable them to achieve what they want in their lives. We are going back to the roots of why most of us started doing what we did, before we got frozen into bureaucratic accountability.

16. People with HIV in Residential Aged Care

Catherine Barrett: Community Liaison Officer

I work at Gay & Lesbian Health Victoria and The Australian Research Centre in Sex Health & Society. I've previously worked as a Unit Manager in Residential Aged Care Services. I've done some work with the National Aging Research Institute and had a business for fifteen years, trying to create a revolution around sexual expression and aging without much success. I've also worked as a Quality Assessor for the Aged Care Standards & Accreditation Agency and have authored a report telling some of the stories of GLBT people in aged care services. When I finished the report I sent it to the Aged Care Standards & Accreditation Agency. They said they would read it with much interest. I haven't heard back from them but they are certainly aware that we are out there which is great.

I'm not an expert in HIV/AIDS but I've had the privilege of working with Mike Kennedy and Lizzy Craig in Melbourne. I've interviewed a gay man who is living in residential aged care services who has HIV and has quite an extraordinary story, parts of which I'll share today. And so I find myself, I don't know, maybe as an Aged Care Whisperer. If that means having a passion for aged care and bridging the interface between some of the things that are happening outside aged care and with aged care itself.

I'm going to start with some images

I finished my training in 1980 and I worked in a benevolent asylum, which had Florence Nightingale type wards - lots of brown tiles that had been varnished very cleverly in the 1970's. The image of aged care then was that it was about old men and women who were very frail and vulnerable, and the care that we provided, with the very best of intentions, was about doing things to them. Another important image I have is the crocheted blanket. We had piles and piles and piles of crocheted blankets and we also had piles and piles and piles of plastic beads and every year for Christmas we gave everybody, with the very best of intentions, lots of plastic beads and we thought we were terrific, we really did. It is very different now. Over the twenty five years that I have been working in aged care, it has changed enormously and fabulously but there are some things that remain the same, and one of them is the stereotypes about aging. Some of these images are at one level hilariously funny while at another level, they are not ok.

There are an enormous number of cartoons on the web about older women's breasts being saggy and there are a lot of images about older people not being sexual, about them not being sexually desirable, and that is a really important context I think for aged care services that are caring for gay men that are HIV positive or for gay men.

This is another image that I think is a bit more controversial than the last. It is Sofia Loren posing at seventy two years of age - posing for the Pirelli Calendar. At one level we could say isn't that fantastic an older woman has made it to the Pirelli Calendar but then she's only on the Pirelli Calendar because she doesn't look like she is seventy two.

This is a postcard collage I did when I applied for funding for an Appreciative Enquiry Project. The postcard relates to the care provided in my unit when I worked as a Unit Manager. It says, "Edna had no family so my staff took turns to sit with her and hold her hand when she was dying. I felt so proud". The project was funded. It employs an appreciative enquiry approach very different from what happens in the community: pointing the finger and saying 'not good enough'. All the time I've been working in aged care services, I think I have provided extraordinary levels of care while listening to constant media reports about it not being good enough. I don't suggest we turn into Pollyanna Harringtons but I think there needs to be a balance and I think that when we look at some of the deficits we need to look at why they exist. Our response need not be about hitting people over the head with a stick. It can be a positive response.

The song 'Take all of me, can't you see, I'm nothing without you' has resonance. When preparing the *My People* report, I interviewed Tom. The second time I sat down to interview him, he sang to me 'Why not take all of me' about the fact that as a gay man he felt he had been disowned by his family, and then as a man who is HIV positive, he felt that was unpalatable to his carers. He wanted to say ... I have these lips and these arms but I just can't use them and there are parts of me that you don't want and why don't you take all of me? So I'm going to read you part of his story. (I also want to acknowledge too that while my work has been around the GLBT community, the feedback I've had has been mostly around gay men, so my apologies for the limited focus.)

My name is Tom and I've been in a nursing home since I had a stroke four years ago. I had the stroke because I've got HIV. I've got two brothers and one sister but we don't talk because I'm gay and I've got HIV and they disapprove. I've got no one in my life now that loves me, except the old girl, she loves me. When mum goes I'm done. Because I'm gay, I'm a lonely man. Oscar Wilde said 'City life, millions of people living lonesome together.

When I came here I told the staff that I was married and they started asking to see the pictures of my wife. Of course I didn't have any and because they knew I had HIV they worked out that I'm gay. I can't talk to the staff about being gay because I'm worried my care will be worse. I'm not able to live a gay man's life here because there is no privacy and there are rules and some people think that gay is disgusting. I keep my mouth shut. I have to be careful how I act and careful of what I say. I'm only sixty-four but I'm an old man. The HIV makes me feel old and this place makes me feel old. I've got no one to talk to here because the residents sleep all day and they have dementia. My mind is still good but I have no conversation. I talk to Lizzy;

she's my Community Worker from the Victorian Aids Council. I talk to her about how much I miss sex, touch and intimacy, but I can't talk to the staff in here about that. When I realised there was nothing for me in here; that I had to forget about a sexual relationship with a male, my libido was extinguished.

For years I rallied against this place, and then I got depressed and succumbed to it. I need to meet interesting people to make me feel alive again for a while and then back to this deadness. What else is there, I can't talk to them. I'm a reasonably intelligent man. It's depressing being in here so I started on anti-depressants. They're called happy pills. I had to go on them when I came here. It's depressing.

I've got extra services because of the HIV. People who know about HIV come here to help the staff look after me. I have Lizzy who organises volunteers to take me out for a latte, or a beer or a drag show. They've helped with my HIV and they've changed the way staff treat me. See they are used to gay men and I can be a gay man when I'm with them. They've educated the staff about how to care for me, so I get better care. They check that I'm getting the right care. The staff here know that there are people who are interested in what happens to me. That makes a difference.

The services that come in for my HIV have made some staff take an interest in gay culture. One Nurse wants to come to a drag show with me. That's good because a lot of straight people don't understand gay people. The other benefit is that the services understand gay men, so it's my chance to be with my kind of people. When I'm with them, I come alive. We can talk about the old times and I can be myself. Lizzy says there are more gay men with HIV like me who are going to need aged care. Can you tell them my story so that they get looked after as well and don't get lonely like me?

So that's a very powerful story from Tom. The legacy goes on because we have continued. So we collected stories as the first part of the project with Matrix Skilled and Vintage Men, which are two organisations in Victoria caring for and advocating for older gay and lesbians. In the second part of the project, we gave those stories back to Aged Care Service Providers and asked them: what do you think? It was quite extraordinary, giving staff some snippets from Tom's story and asking them what they thought.

We asked 'How would your facility go caring for somebody like Tom?'. One nurse in high care, Penny, had a response that was typical: 'People would over-glove. There is always staff that would go too far. I don't think staff have nursed enough HIV. They would freak out'. And then there was another Nurse I spoke to, Hazel, who said 'Some staff might steer away from Tom and not go near him and avoid nursing him. They need the facts about how HIV is transmitted and whether there is going to be any danger for them'. So you're probably getting the picture. These are a group of people who haven't really encountered somebody with HIV/AIDS and really don't understand what to do, how to respond and were completely terrified.

I want to share with you one other story. The stories in the *My People* report were a really important part of that research we did because it humanised some of the issues. Here is the

story of Phillip, a man I was invited see in a residential aged care facility. Phillip had been in a relationship for forty-nine years before his partner died. Two years later, his dementia was no longer manageable at home and he went into a Residential Aged Care facility and thought that one of the other residents in the unit was his partner, so he would quite often sit next to the other resident and hold his hand and stroke his face. At one stage he was found with his hand on the other resident's thigh, and at another point he was found in another resident's room with his pants down. Nobody was quite sure why, he may have been going to the toilet, I don't know, but the staff were absolutely petrified. Staff spoke to the residents' brother who then said 'My brother is gay' and staff were really frightened then and they asked the GP to prescribe Andricur: a testosterone suppressant also used as a libido suppressant. They really did not know what else to do. They were absolutely petrified.

I agreed to do some work with them and we ran a series of focus groups with nurses and Personal Care Attendants who volunteered to work with me. The first thing I did with them was ask, 'Why did you volunteer to be part of his network of carers reviewing his care plan?' and each and every one of the seven or eight of them put up their hands and said, 'My son is gay', or 'My sister is a lesbian', or 'My neighbour is gay', or described a relationship with either a gay person or a lesbian. They felt that the issues were about Phillip's humanness: not about his sexual identity. Even so, when they realised Phillip was gay, one of the things they wanted was to test him for HIV. One of the staff said to me in one of the focus groups 'We don't have the information on whether or not he has AIDS. I feel sorry for the poor Personal Care Attendants that go in there and don't wear gloves to protect themselves. If they get AIDS who are they going to sue?'

Seriously, if I brought these women and men into this room you could sit down with them and they were gorgeous people but they had never been educated on how to care for someone with HIV. A number of them didn't understand what being gay meant. In fact somebody said, 'Well if we get many more gay people we might have to build a separate lounge so they can all sit together and have sex because they can't be having sex in front of the other residents'. There is a sense of good will but they don't know, they haven't been told, they haven't been taught ... and I don't think we can point the finger at them for not knowing. I think what we need to do is tell them what it is they need to know.

Here is a map relating to gay legislation in the world. Importantly, in Residential Aged Care Services there are a lot of workers now from Africa, from India, and from the Philippines. In some African countries and in India, being gay is punishable with anything between eleven months to life imprisonment. For somebody who has come from Africa or India, who finds themselves working in Residential Aged Care and who meets a gay man for the first time, what is that like for them? How do they put aside everything that they have learnt while growing up? One of the things we do at Gay & Lesbian Health Victoria is work around inviting Carers to look at the 'I' factor. Where are they coming from? What are their values and beliefs? How do they respond to the cartoons of the older woman with the pierced nipples? And what are the stereotypes that they subscribe to?

For some, a gay man with an extraordinary high profile may be the only gay man they know of. They may have met gay men before, but they don't know what it is to be gay. They have absolutely no idea. They think it is about who you have sex with. That it is not about culture. So, because older people aren't expected to be sexual and because being gay is just about

sex, then the comment made by staff about Phillip was that he 'used to be gay'. So he is no longer sexually active. One of the staff told me, 'We could tell he was gay. I knew he was gay. As soon as his brother told me he was gay I knew, walking around with that day pack on'. You know, there's really no sense of what being gay is.

I am going to finish by referring to two funding proposals that we have submitted but missed out on. We applied for Victoria Health funding to develop a resource kit to assist aged care services to prepare themselves to care for people living with HIV/AIDS. We thought that a core component of that would be interviewing people living with HIV/AIDS so that their stories could be told, because that seems to be a really important connection point. The other funding we put in for was with the Nurses Board of Victoria. We wanted a nursing focus on areas of difficult communication, particularly around HIV, sexual identity and how nurses can keep themselves safe. Nurses wanted to understand how they could initiate those conversations with other carers and how to engage somebody who wasn't really interested.

A couple of other projects we have got up and running are Everyday Angles, the post card project, and Val's café: a coffee lounge we are running four times a year in collaboration with Gay & Lesbian Health Victoria and the Also Foundation in Victoria. We invite Aged Care Service Providers to come to the Also Foundation for coffee and cupcakes and to be looked after, because we think that they need to be looked after – they deserve to be looked after – and we want to support them in the championing work they are doing caring for the older GLBTI people in facilities, which they may be doing on their own. The other thing we are doing is some work called Storyboarding for Aged Care Service Providers and we are going in and educating Aged Care Service Providers on sexual expression and ageing – the importance of it and where GLBTI ageing fits in that.

17. A Community Partnership – AACACT & United Care

Nada Ratcliffe: AACACT

This presentation is about two like-minded organisations coming together over a community event. This is about:

- Community development
- Mainstreaming
- HIV and Ageing
- Partnerships
- Legislative reforms
- Supporting our communities

Although there are various elements to the relationships, it is foremost about community: about developing flexible services for an ageing population affected by HIV. This is about recognising a genuine need: walking the talk. The personal is political.

The successful Australian response to HIV has been based on partnerships across various levels. We are focused on better lives for men, women and children and all those affected by the virus. In smaller regional areas, partnerships work particularly well as specialist services are often not available. The ACT is relatively small. The AACACT and PLWHA ACT are the

only community sector agencies in the region specialising in minimising the impact of HIV on our communities.

Current partnership successes

- **Community/government** The ACT Special Needs Dental Health Program works in partnership with ACT Health (community/government). For positive people, dental issues can be serious and they can be frequent. The program commenced in 2005, with clients referred through ACT Dental Health Service. This program is working extremely well.
- **Community/community** The partnership with the Havelock Housing Association Inc. (the largest provider of community housing in the ACT) provides:
 - Dedicated Community Housing
 - Long term accommodation
 - Income based rental

The project is currently accommodating seven people affected by HIV: 1 large family and 1 couple. We are waiting for another property to be allocated.

- **Community/corporate** This pilot project commenced approximately three months ago. The AAC Legal Advice Service (based on partnership with a private firm) includes free legal advice sessions with an experienced legal practitioner and a registered migration agent who is a member of the HIV-positive and GLBT community.

Partnerships are useful in this aging environment where more people than ever are living with HIV and large numbers of people are ageing with HIV. We are addressing issues around:

- ageing
- bio/psycho/social issues of ageing
- frail aged
- unable to fully self manage
- wanting to maintain independence
- need for day to day support
- special needs relating to HIV

We recognise that every situation is unique, and for example, we are providing support to individuals and to families affected by HIV.

Some might say 'leave it to the mainstream. Getting frail and old is getting frail and old but specialist services take account of the real difference of living with HIV and address issues around the way positive people are treated, for example, entering a nursing home or having someone delivering care in their own home. The loss of control over one's body, home and social life is difficult for all, but can be far harder for positive people if confronted by others' ill informed views.

Community Aged Care Packages can be very effective as they are individually designed and managed. They provide a planned and managed package of community care, for those with complex care needs, wanting to remain living in their own home. Services can include:

- meal preparation
- laundry
- assistance with continence management
- transport
- personal care
- social support
- home help
- gardening, and
- temporary in-home respite care

Partnerships - For a partnership to work, it is most important that agencies have shared values. The partnership between AACACT and Uniting Care Ageing works, in part, because we share similar values:

Values:

AACACT

- Strive for excellence
- Empower individual & communities
- Commit to shared responsibility
- Promote equity of access, dignity & respect

Uniting Care Ageing

- Courage
- Compassion
- Growth
- Respect
- Integrity
- Community

Roles:

AACACT

- Circulate information through networks:
 - Men & women with HIV
 - Partners & family members
 - Affected communities
 - Medical practitioners
 - Other medical services
 - Allied health professionals
 - Community organisations
 - Aged care services

Uniting Care Ageing

- Staff recruitment
- Staff management
- Administrative
- Output reporting
- Ongoing collaboration

Staff training around LGBT sensitivities, and ongoing monitoring and support are vital. Similarly, clients must be able to contact the agency and a complaints procedure be put in place.

The partnership will potentially deliver a high quality flexible service to assist people living with HIV and affected communities to remain living independently in their own homes. If the partnership is not successful, the process will have included:

- good networking
- relationship building
- awareness raising (including among bureaucrats)
- putting the issue on the table
- reinforcing a sense of community
- reinforcing the issue internally
- opportunities for reflection & review

Case Studies

18. Smoking Cessation

Jeanne Ellard: Research Associate, NCHSR

Effective treatments have reduced the mortality of people living with HIV but the proportion of deaths not related to AIDS defining illnesses has increased. Cigarette smoking in HIV positive people increases health risk: lung infection, PCB, TB, non-AIDS related cancers and cardiovascular disease. Preliminary research suggests smoking may impact uptake of ART but that research is not conclusive. Concurrently, HIV positive people have significantly higher rates of smoking: estimated in *Futures* puts it at some 47% compared to 23% in the general population.

In treatment accessing patients, non-AIDS related illnesses are now the dominant cause of death, with tobacco smoking a predominant risk factor in many of the illnesses implicated in HIV. Most of the literature now suggests that smoking related interventions must become a priority and integral part of the HIV response, as that has the potential to reduce the disease burden and increase the quality of life of those living with HIV.

The AFAO literature review I have developed, which considers smoking cessation interventions targeting people living with HIV or with potential for that focus group, will soon be available. The report covers:

- barriers to quitting
- relapse
- the role of social support (as facilitator of smoking and of quitting)
- the broader impact of smoking among the GLBT community
- behavioural, pharmatherapy and tailored interventions
- the potential of internet and mobile phone based interventions

The literature suggests there are some benefits of smoking including pleasure, facilitating and sustaining social engagement (which may be of particular note for some positive people), and reducing stress. Some of the disadvantages are the expense, addiction being inconvenient and controlling, and harmful everyday health effects (e.g. coughing and sinus). There appears to be a lack of awareness of the unique threat of the association of smoking and HIV. There has been a sense that for a long time that people with HIV believe that because they have such a serious disease they need not worry about smoking: a view possibly shared by many clinicians not wanting to add to the burden of those with HIV by suggesting they quit smoking.

The research suggests many people have an interest in quitting but are concerned about stress, anxiety and depression, so obviously any interventions needs to consider those factors. Importantly, the research also suggests quite significant health benefits can be achieved in a short time. One study found observable benefits after three months. There is no sense in the literature that 'quitting' is less appropriate for a person who has already experienced AIDS defining or other illnesses.

Clinicians play a significant role in smoking cessation. The general literature suggests the combination of effectiveness and cost effectiveness comes out in favour of consistent, brief interventions. So every time a professional sees a patient or a client they should ask about smoking, suggest quitting, assess willingness to quit, and assist with that and arrange follow up. As little as three minutes is seen to be effective, both in Australia and internationally. Despite that, health professionals are not routinely doing so. In Australia, a survey found only 34% of clinicians reported giving smoking cessation advice during routine consultations with patients who smoke. Obviously, many positive people have regular and ongoing interactions with healthcare professionals so that opportunity is there. Diagnosis appears to be an optimal time for intervention because it is a time when people are receptive to lifestyle and behavioural changes.

Pharmacotherapy is high on the list of successful interventions. There is strong evidence that combined with behavioural interventions, e.g. counselling, it is one of the most effective approaches. There is also clear evidence that targeted interventions (including population-targeted) are highly effective. Although there is very little research on PLHIV around smoking cessation interventions, what there is suggests interventions targeting PLHIV are very effective. Further, that is the case for gay men. The majority of PLHIV are gay men with equivalent high rates of smoking. Interventions likely to work well target broader GLBT community because that is where PLHIV are likely to smoke. Alternatively, alternative therapies such as acupuncture and hypnotherapy-type interventions seem to be unlikely to help. Also self-help mass produced booklets have low success rates, partly because they do not include additional assistance (whether pharmacotherapy or counselling). There have been some studies using phone based therapy that has shown some success. There doesn't seem to be a lot of difference between group and individual counselling as long as the content is robust. Also, if people are without social support, that can be a real problem.

19 Flinders Model of Chronic Disease Self Management

Nada Radcliffe: AACACT

The Flinders Model of Chronic Self Disease Self Management is

A generic set of tools and processes that enables clinicians and clients to undertake a structured process ... for assessment of self managing behaviours, collaborative identification of problems and goal setting, and the development of individualised care plans. (Flinders Human Behaviour & Health Research Unit, 2006)

What does it mean?

- Collaboration
- Personalised Care Plans
- Self-management education
- Adherence to treatments
- Follow up and monitoring

What is self-management?

Self-management is enabling. It involves engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning emotions and interpersonal relationships, and adhering to treatment regimes. Self management includes:

- making informed choices
- gaining new perspectives
- gaining new skills
- practicing new health behaviours
- maintaining or regaining emotional stability

The Flinders Model recognises that the greatest resource for a person with chronic conditions is the person with the chronic condition. People with **chronic** conditions are the principal care-givers. 'Each day, patients decide what they are going to eat, whether they will exercise and to what extent they will consume prescribed medicines.'

(*Bodenheimer et al, JAMA 2002*) Health care professionals should act as *consultants* supporting them in this role.

The six principles of self management are:

- knowledge of one's condition
- follow a care plan
- actively share in decision-making
- monitor and manage signs and symptoms
- manage impact on physical, emotional and social life
- adopt lifestyles that promote health

The care plan should include:

- Identified issues and identification of the main problem
- Agreed goals
- Agreed interventions
- A sign off
- Review dates

The Flinders model aims to improve relationships between clients and health professionals, and to include collaborative efforts to identify problems and target interventions. It may lead to ongoing behaviour changes and it may be motivational. The model also allows for measurement over time, and has a predictive ability, so it can predict enhanced health outcomes based on changes to behaviour. Outcomes should include identification of issues, development of individualised care plans, and monitoring and reviewing.

Courses are available for health professionals to understand and use the model. These include the Graduate Certificate in Health (Self-management), and the Graduate Diploma in Chronic Condition Management.

Case study

This case study relates to a 45 year old single man, living alone. He has been a client of the mental health service for 20 years. He is diagnosed as having paranoid schizophrenia, and has a history of violence (including two incidents during worker home visits). The client smokes cigarettes and is benzodiazepine dependent - engaging in doctor shopping. The client has problems with planning, concentration, memory and problem solving, as well as persistent paranoia. He is subject to a treatment order.

The client set a range of goals including developing a better body image/decreasing weight, decreasing benzodiazepine use, improving his financial situation, and taking better care of himself and his dog.

Outcomes

Through application of the Flinders model, the client:

- Signed a cleaning contract for five weeks aiming to feel better about his house, so he could do weights and be able to invite friends into his house, which in turn boosted his self esteem and challenged the view of him being dangerous to others
- Reduced benzodiazepines, and committed to seeing only one doctor with greater disclosure to that doctor
- Was found to have a poor knowledge of his condition and his treatment, which was addressed
- Agreed to have a single worker undertake home visits
- Has begun his next goal of cigarette reduction
- Has engaged in more social interaction, and is less paranoid

Flinders vs Stanford Model – There is some discussion of the similarities and differences between the Stanford and Flinders models. These might be summarised as:

Stanford

- Utilises a group setting
- Trains & uses peer educators
- Standardised structured sessions

Flinders

- Underpinned by Cognitive Behavioural Therapy (CBT)
- Generic approach
- Client centred
- Between the individual & health professional/s
- One on one model

In the ACT the local territory branch of the Division of General Practice have employed a project officer to co-ordinate a chronic conditions self management project. Partners include:

- UNSW Centre for Clinical Governance
- ACTDGP
- ANU College of Medicine and Health Services
- Australian National University

- ACT Health Aged Care and Rehabilitation

The project will run for three years and be named 'The inter-professional learning in primary health care to encourage active patient self-management of Chronic Disease'. One of the key roles is to establish a joint consumer and health professional network. The ACT Chronic Conditions Alliance was formed as a consumer network to inform the project. It is a network of community organisations and groups working together to improve the quality of life for those living with a chronic condition. The Alliance aims to:

- present issues of concern
- promote information exchange
- lobby for relevant health services
- bridge the gap between government and NGO's
- collaborate in the development of health services
- be a communication channel for organisations to engage with chronic conditions groups and services

Other challenges include:

- comprehensive training of medical practitioners and allied health professionals
- involving both personal commitment to the process and outcomes, and a commitment to the significant time required
- practitioners working within an holistic framework

For further information on the project, please contact:

- Flinders Human Behaviour and Health Research Unit
- Sharon.lawn@fmc.sa.gov.au or Malcolm.Battersby@fmc.sa.gov.au
- <http://som.flinders.edu.au/FUSA/CCTU/Home.html>

20. CALD Competency Workshops/Training

Nandina Ray, Clinical Supervisor, MHAHS

MHAHS is a state-wide service funded by NSW Health, based at Royal Prince Alfred Hospital in Sydney, although funding for The National Cultural Competency Project (ran 2006 to 2008) was from the Commonwealth. MHAHS is responsible for advocacy, community development, ethnic media workforce development, and client support. There are 16 full time staff and 80 casual bilingual and bicultural staff working across 25 languages.

The National Cultural Competency Project aimed to develop and pilot a cultural competency training program to increase the capacity of HIV services and organisations to work with culturally and linguistically diverse communities and increase the inclusion of PLHIV from CALD backgrounds in strategic planning of HIV services.

Cultural competency was defined as requiring individuals and organisations to have a defined, congruent set of values, principles and demonstrated behaviours, attitudes, policies and structures that enable them to work effectively cross-culturally. It is more than an awareness of cultural differences - aiming to improve the health system's capacity by integrating cultural difference into health service delivery.

Cultural competency can also be seen as a combination of behaviours, practices, policies, structures, and attitudes, as all affect each other. Cultural competence is a framework as well as a process. It is an ongoing developmental process for the worker, the agency and the system in which they work.

Why is cultural competence so important for HIV services? Twenty two percent of HIV notifications between 2003 and 2007 were from people born in non-English speaking parts of the world. CALD populations are often associated with low testing rates and low presentation. CALD populations are a priority in the national and NSW strategies. And the profile of HIV reflects different pattern of risk, with notifications almost equally divided between gay men and heterosexual women.

A major component of this work was an assessment of cultural competence of HIV services throughout Australia, done through an online survey. Three hundred and twelve completed surveys were received from agencies including clinical services, AIDS councils, clinical services and Needle and Syringe Programs.

Most participants reported that people from CALD backgrounds accessed their services. 63% of people from CALD backgrounds were a priority for their services. There were mixed results when organisations responded to whether or not they believed their organisation was culturally competent. Some of the key challenges were:

- Language and communication
- Knowing how to access CALD communities
- Having an understanding of different communities
- Differing values and beliefs
- Inadequate resources

The majority responded that services could be improved only if all aspects of CALD competency within the organisation were improved.

The implications are that we have an experienced workforce working with CALD communities but we need to provide a generic set of skills for working with people from a range of CALD backgrounds (although there is no formula), and to focus on the overall organisational capacity and response.

Three levels of cultural competence were developed:

- Individual – direct interaction with CALD clients
 - Recognising and understanding cultural diversity
 - The influence of culture on health
 - Stages of cultural competence
 - Case studies
- Population - how to work in CALD communities
 - How to identify priority populations
 - How to make contacts and links
 - Increasing access to populations (eg. media, partnerships, plain English text)

- Organisational – how to embed cultural competence
 - Workforce development
 - Recruitment
 - Service planning

All three need to be working equally well for cultural competence to be effective. The training package was developed to be delivered to whole agencies at one time: so the agency was the unit of intervention. Three lots of three hour modules focused on the three different levels. Before commencing training, managers were supplied with an audit tool to be completed prior to training. After training, feedback was provided to the agency with areas for further development, and a follow up service was provided.

The training was delivered to six organisations nationally with some 50 participants. Positive feedback was received as well as feedback for improvement. Further requests for consultancy based training are being received. Positive outcomes have included agencies implementing some of the suggestions made during training. The cultural competency training has just been adapted for Hep C.

An external evaluation, including participant evaluation and in depth interviews, found high levels of satisfaction, relevance and usefulness. Participants reported an increase in knowledge, self-efficacy and skills to work with CALD populations. The content and training methods were found to be well received. The attendance of managers was integral to agency success, with participants valuing the focus on the agency rather than individual workers.

21. Phoenix

Peter Thompson: Bobby Goldsmith Foundation (BGF)

By the time a positive person arrives at BGF, the wind has usually gone out of their sails. They have lost direction. They lose control over direction because they have lost control about what to do about life. Everything has been concentrated. I often say to clients, 'Don't give the virus any more power than it actually has', because often there is a concentration on the idea that everything that has gone wrong, has to do with the virus. In fact, the virus has been a much later introduction to the range of their problems.

The Phoenix workshops were born out of an area we call 'positive futures', which I think speaks for itself. The Phoenix workshops started off in a very small way and have since been broadened. In the main, the objectives are to:

- improve optimism about the future
- build confidence
- initiate positive change

Basically we are trying to empower people to take charge of their lives. We work on a model that battles the welfare networks, the sense of dependency and reliance. The Phoenix workshops are about identifying there is a need to break some of that dependency. It offers participants:

- Space and time to consider what change is possible
- Strategies to consider ways to balance and affect changes
- Advice on work, study and volunteering options
- Advice on other services, e.g. job network, TAFE, universities
- Advice on legal implications and effects of Centrelink benefits
- Ongoing support and assistance throughout the process

Around the time the project came into being, the organisation took on a change in how it delivers its services. That came out of consultations with clients, service providers and other identified groups. There is a great deal of flexibility in content, so that the needs of the individual may be addressed.

Our work includes working with clients to:

- set realistic goals - often in situations where people are living with depression and other challenges and they focus far into the future - which is difficult to do. Instead, we are trying to focus on each little step and celebrate that. Often that involves changing something deeply entrenched that has gone on for a long time.
- manage a balanced and healthy lifestyle, which includes a broad range of things. We have found that when working with CALD groups, you have to be part of the event, maybe singing and dancing etc. which is culturally challenging for me, but it shows the diversity of people affected by HIV.
- challenge negative thinking and work on resilience
- manage change and manage stress
- provide information and advice on work study and volunteering
- meet challenges of returning to work (not necessarily paid work)
- develop financial planning and budgeting
- update and rewrite a resume - often if a person has been out of the workforce for some time, they lose sight of the fact they have skills.
- develop more effective communication skills
- disclose HIV status
- build self esteem

Phoenix workshops are flexible. A formal workshop may take the form of four to six weeks but they can have flexible delivery as they are to meet participants' needs. They aim to build individual confidence through group participation, and there is some effort put into socialisation, and often relationships do develop. We may use weekdays or weekends. We endeavour to use local services, so if we are outside Sydney we try to use local services. Also, if we are talking about Centrelink we try to use someone from Centrelink.

We have a package of Phoenix workshops:

Luncheon Club - offered in conjunction with ACON. We offer a 1 ½ hour workshop at the end of lunch depending on that group's needs. For example, it may be about housing or a specific Centrelink issue that ACON is not currently addressing.

Phoenix Semester - participants are selected from BGF client list and invited to participate. The clients are supported throughout the workshops, and three months later there is follow

up done. Linked to workshops, there is also follow up done by their case worker (as each client has an allocated case worker working with them on their integrated service plan). Committing to an eight or 12 week project, and it may be ½ day/week, may help them move toward further commitment in relation to study or work.

Weekend Phoenix - may have similar content to other workshops but will be condensed depending on where the group is located or the needs of the group. Sometimes we may seek sponsorship through a partnering organisation or area health service.

Phoenix Resilience – may be run as part of a Weekend Phoenix or can be a full day intensive program delivered by the Iris Consulting Group which has developed the resilience mastery program.

Phoenix Quest – a five day program delivered in partnership with King's Quest Organisation. This is also a program that requires sponsorship. It is an intensive and life changing program.

Groups are usually of between six to twelve people.

My experience in delivering some modules in the programs is that for many participants it has changed small things that have made a huge difference. A lot of the work is about changing perceptions and outlook, and some participants have made tremendous changes. The choice of the word 'Phoenix' was a great way to communicate that this bird can reinvent itself. It can regenerate. It is invincible. And that is what we are communicating about the human spirit. Phoenix offers the participants tools and inspiration to discover that new life.