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SUBMISSION ON SYSTEMIC BARRIERS AND STIGMA AND  
DISCRIMINATION EXPERIENCED BY PLHIV IN ACCESSING  
HEALTH SERVICES FOR HEPATITIS B, HEPATITIS C  
AND/OR HIV PREVENTION, CARE OR TREATMENT.

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**napwha** national association of  
people with HIV australia

## EXECUTIVE SUMMARY

There are still systemic barriers in accessing HIV prevention, care and treatment in Australia. Systematic means that they are inherent in the overall system, and are repeatedly encountered. Through the gathering of information from key informants within the networks of PLHIV in Australia and through documenting some recent case studies it is identified that there are still 'system-wide' issues that confront PLHIV in accessing health services. The 7<sup>th</sup> National HIV Strategy notes that HIV care is increasingly accessed in mainstream services – one major systemic barrier identified, is that there are still workers involved in the health care system who do not seem to be aware of the current knowledge and understandings of HIV disease management. A number of anecdotal stories indicate that it doesn't matter whether the point of intersection with the health system is a major hospital, a suburban GP clinic, a regional dental practice, a rural primary health care facility or a referral for counselling – there still seems to be a lack of knowledge by some working in the health care system of appropriate protocols and ways of managing people who have HIV who are needing health care at any particular moment. NAPWHA thinks that pre-service training in HIV for all health care workers in Australia needs to be updated. This links to the experiences of stigma and discrimination that are still encountered in health care settings. Stigma, understood as an attitude that others hold against a person with HIV and discrimination, understood as an act which unnecessarily differentiates a person living with HIV from any other person presenting for care, are still being experienced by PLHIV. Priority actions 7.4 identified in the 7<sup>th</sup> National Strategy that relate to workforce development require ongoing attention in the context of reducing stigma and discrimination experienced by PLHIV:

- Ensure that HIV testing and treatment providers have adequate training and support to deliver appropriate services.
- Work together with relevant organisations to ensure delivery of responsive and coordinated training, continued education, and professional support programs, including in regional and remote areas and for new workforce entrants.
- Improve collaboration between mental health, drug and alcohol, disability, clinical and community services to address the care and support needs of people with HIV.

This is not to say that there aren't many different points of intervention that need to be pursued to reduce HIV-related stigma and discrimination, but of those which relate to accessing health services, workforce development issues are perhaps one of the most significant points of intervention.

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## ABOUT NAPWHA

NAPWHA provides advocacy, policy, health promotion, effective representation, and outreach on a national level. Its work includes a range of health and education initiatives that promote the highest quality standard of care for HIV-positive people. NAPWHA also contributes to clinical and social research into the incidence, impact and management of HIV. NAPWHA's vision is of a world where people with HIV live their lives to their full potential, in good health and free from discrimination. NAPWHA:

- represents the needs of HIV-positive people, especially those dealing with treatment issues, clinical trials, disability and support services, welfare issues and health promotion strategies
- lobbies government on a range of HIV-specific and broader health and social policy issues
- collaborates with service providers to ensure that the current needs of positive people are met
- participates in community-based education and health promotion initiatives
- develops and contributes to policy across the health and welfare sectors
- fosters partnerships with government, the research community, HIV clinicians, the pharmaceutical industry and other consumer health and disability groups
- assists state and local HIV-positive organisations and groups to undertake advocacy, education and policy work

## INTRODUCTION

Recent claims that the HIV epidemic in Australia has now been successfully managed due to the availability of new and better treatments as well as new prevention technologies perhaps, unfortunately, promotes a public message that all aspects of management of HIV disease have now been dealt with successfully in Australia. People living with HIV (PLHIV) continue to have doubts about that – the persistence of HIV-related stigma and discrimination, over thirty years into the epidemic continues to confound many people – especially PLHIV when they encounter it. If not only confounds, but confuses and angers PLHIV when patterns of stigma and discrimination continue to occur. Stigma and discrimination also have direct consequences in terms of access to care and treatment when it occurs in health care settings. Systemic barriers in terms of access to treatment and health service for PLHIV are still evident within the health care system.

PLHIV who have other different identities including - gay men, women, bisexual men, heterosexuals, Aboriginal and Torres Strait Islanders (ATSI), people who use and/or inject illicit drugs and people from Culturally and Linguistically Diverse (CALD) backgrounds have provided recent case studies which indicate that there continue to be instances of stigma and discrimination occurring in health care contexts. Information provided in this report is not exhaustive but indicative of the fact that problems still remain. The information from case studies provided to NAPWHA, for the purpose of the writing of this report, is accompanied by information from relevant literature in Australia; and also where useful, some ideas have been drawn from conceptual work on the impact of stigma, discrimination and systematic barriers to the management of HIV disease from the other countries.

This submission also provides some reflection on key concepts which are often described as principles in what is termed Universal Access to HIV prevention, treatment and care. Availability, accessibility, acceptability and quality (AAAQ) of treatment and care programs in Australia is important to PLHIV. These principles are also important in the context of the treatment as prevention approach (TaSP), unless the AAAQ principles are actually enacted throughout the whole health system then the approach effort to reduce the impact of HIV disease on those who are HIV positive and the aims to reduce and eliminate HIV transmissions in Australia is put at risk of being undermined.

Noting again that structural barriers are those that are inherent in the overall system it is argued in this paper that just concentrating on patient empowerment models to overcome stigma (perceived or real) will not be enough of a response. One way of understanding the case study material is that PLHIV have reported being judged from a moral standpoint, and this is stigmatising or there have been instances of unprofessional and unethical Health Care Worker (HCW) behaviour and this is discrimination.

There is certainly, from the information we have collated a significant systemic problem. The problem is that not all areas of the workforce seem to be receiving pre-vocational or post-vocational training on HIV that is keeping all HCWs up to date with current changes in the control and management of HIV. General practitioners, specialist service and publicly funded sexual health services play an important role in meeting the changing needs of people living with HIV; but also the workforce managing people living with HIV includes nurses, psychologists and psychiatrists, dentists, drug and alcohol workers and other ancillary health care workers. Consistent workforce education around HIV seems to be a structural problem. Other systemic barriers will also be noted as they relate to particular identity groups, for example women, ATSI people and people from CALD backgrounds.

## THE EXPERIENCE OF STIGMA AND DISCRIMINATION IN THE COMMUNITY OF PEOPLE LIVING WITH HIV

### STIGMA

A general understanding of the impacts of HIV stigma is that it affects not only PLHIV directly but has negative consequences on the entire community through perpetuating fear and false information about the HIV virus or the person living with HIV. Stigma discourages:

- people from accessing or getting tested,
- accessing treatment and/or
- disclosing their HIV status to friends and family or in the workplace

PLHIV in Australia have been responding to the experiences of stigma since the epidemic began. Recent examples aiming to deal with stigma at a community level include 'The Enuf Stigma and Discrimination' campaign and Senior Voices project sponsored by Living Positive Victoria. Other organisations such as Positive Life NSW or Queensland Positive People describe their positive speakers programs as being one way in which they attempt to respond to stigma at a community level - the visibility of PLHIV is believed to combat stigma. On another level PLHIV are encouraged to develop personal strategies to build resilience and combat the effects of stigma and there have been various attempts around Australia through community based organisation to implement personal empowerment strategies for PLHIV (eg. the Positive Leadership Development Institute). Building resilience as a strategy for responding to stigma was suggested by the NAPWHA Stigma Audit conducted in 2012 but other recommendations from that report are worth recalling here:

1. Initiatives that aim to build resilience among people with HIV should be developed. This should include cultivating specific skills for combating HIV stigma and a broader set of life-enhancing skills that improve wellbeing.
2. Opportunities for promoting resilience should be explored and exploited in the current body of education work occurring in the community-based response to HIV.
3. Anti-stigma work, including campaigns and events, should avoid the idea that people with HIV are passive receptors of stigma or require sympathy. Such work should promote strong and positive responses that work to enhance wellbeing.
4. A more complex notion of PLHIV quality of life needs to be understood by government departments and others involved in sectorial responses to HIV. The goal of improving quality of life is laudable and the National HIV strategy endorses a holistic approach to wellbeing. There remains, however, an emphasis on physical illness. Overcoming stigma and building resilience should be regarded as key activities in enhancing wellbeing. While anti-discrimination legislation is an essential element in our efforts to fight stigma, stigma is not an issue that is entirely dealt with under the heading of human rights and anti-discrimination.
5. As HIV prevention evolves to include a range of risk-reduction strategies that may or may not include condom use, all such efforts should be reviewed to assess their effects on PLHIV. This includes strategies that encourage disclosure of HIV status and which may reinforce the sero-divide. Consideration should also be given to the different effects on PLHIV of such prevention efforts in settings outside large gay cities where sizeable PLHIV communities reside.
6. As disclosure in sexual settings is highly fraught, legal requirements that require PLHIV to disclose their status in sexual settings should be reviewed. A requirement for a person living with HIV to take reasonable measures to avoid transmitting another person should be sufficient.

Australian research has shown that there are a range of issues associated with HIV stigma. These include problems experienced in relationships, at medical services and in the workplace. Grierson et al. (2011) have reported that from a study sample from the Futures 6 Survey conducted in 2009 that:

- 65.8 % of respondents agreed with a statement that “Few people would want a relationship with someone who has HIV”
- Over half of the respondents reported that they were afraid to reveal their HIV status to their sexual partners for fear of rejection
- Over one quarter self-reported receiving less favourable treatment at a medical service as a result of having HIV
- About one sixth self-reported less favourable treatment in the workplace during the year’s preceding the survey period.

Not all of the above factors can be assumed to directly relate to consequences for accessing health services, some would argue that generally stigma is occurring in the social realm eg. sexual partner negotiation or problems of disclosure at work or with friends and that is different to the intersection of a person living with HIV and medical services. That approach however does not sit easily with PLHIV or with the social determinants of health framework, which sees individual, social and cultural factors intimately connected with health and health outcomes. Of the dot points above, in relation to the workplace, it should be noted that whilst for many, treatments have been simplified and management of side-effects have become less of an issue the necessity to disclose within workplace settings has been removed, however problems still have the potentiality to arise in this area e.g. HIV positive people working in health care settings.

Impacts of stigma on access to health services are much clearer when considering, for example sub-populations of PLHIV. For example Brener et al. (2013) drawing on a study in the Australian context demonstrated that heterosexual PLHIV may feel more stigmatised than gay PLHIV and that there were direct connections then between stigma experienced and lower HIV treatment uptake in heterosexual PLHIV. Other literature has suggested that there is a correlation between experiences of social rejection and disapproval which may decrease the motivation of PLHIV to stay healthy (CAPs 2005) or that psychosocial barriers (Keen & Watson 2012) may still influence decisions to initiate lifelong HIV treatments despite the availability of improved treatments.

Women report high level of concerns about disclosure in social settings and the fact that fewer women are diagnosed with *newly acquired* infection (AFAO 2015) suggests that stigma impacts significantly on this group in terms of accessing health services. For Indigenous people living with HIV (see Negin 2015) and based on case study information provided for this report in relation to CALD communities, even the perception of stigma is enough to deter some individuals from accessing otherwise available services. This point is backed up by some studies from overseas (Obemeyer et al 2011; Shuster et al 2005) making the argument that even the fear of stigma, whether it is real, perceived or enacted, has direct consequences on PLHIV and their willingness to access medical and health services.

## DISCRIMINATION

The general proposition is that discrimination occurs in a health facility or health service by a health worker when a HIV-positive person reports that

- they are treated differently because of their HIV status by the health care worker,
- there is use of excessive precautions by the health care worker and/or
- appropriate care is with-held.

An international review, initiated through the Department of HIV/AIDS, World Health Organisation (which also included review of material from Australia) reported that such experiences of discrimination are declining, especially in high-income countries (Obermeyer, Baijal, Pegurri . 2011).

However, the experience of a decline in discrimination is not universal and there are some specific matters in Australia that require attention. For example:

- More women than men reported fearing discrimination in the form of avoidance of treatment, extra precautions, and confidentiality problems ( Grierson et al., 2011);
- Indigenous people who face social disadvantage and poor access to any health services are likely to perceive that discrimination might be experienced in general health care settings, and the perception alone creates enough of a dynamic to impact on access (Negin, 2015). Mistrust of health services is common and consequent late diagnosis and delayed uptake of treatment occurs regularly in this population group - ATSI members of the NAPWHA group PATSIN have often identified experiences of stigma and discrimination as a key to why this occurs.
- Difficulties encountered by CALD people – some of which are documented in the case studies – are interpreted as discriminatory, even if something is ‘interpreted’ as discrimination then the outcome in terms of access and/or take up of treatments has the same negative outcome.
- The case studies document recent experiences of discrimination by PLHIV in large hospitals in Australian capital cities – experiences of discrimination may be declining but they are still occurring as in these cases where there was involuntary disclosure of a persons’ HIV status.
- In some instances the case studies also document discrimination experienced in a health care setting based on what the person reporting the discrimination describes as ‘moral’ or ‘value judgement’ about their lifestyle choices. On some occasions this has been around illicit and injecting drug use and or sexual practices – not HIV discrimination *per se* but discrimination based on the other perceived deficit practices of that person.
- Another of the case studies is about discrimination experienced in an encounter with a psychiatrist who focussed inappropriately on the sexual practices of a gay man, the psychiatrist provided a written report about that person without any reference to, or knowledge of concepts such as undetectable viral load and included in a report that the persons greatest responsibility in life was to practice safe sex. In other words the psychiatrist was judgemental about the sexual practices of the person being evaluated and had little understand of the current state of HIV treatments.

Adherence to ART on a lifelong basis is, at this moment of the epidemic, a key to effective control and management of HIV. Experiencing health service discrimination has been identified as one of the independent variables associated with increased odds of reporting difficulty or non-adherence to ART (Grierson et al. 2011).

### A note on perceived discrimination

In the previous section it was discussed that stigma can be felt, and/or enacted. The consequence in terms of access to services is still negative as it has the effect of discouraging persons from engaging either at a particular health facility or engaging with their own health management in totality. It is possible that perceived



discrimination (Schuster 2005) can have the same effect. In some of the case studies provided, an argument could be made that the report of discrimination is only a 'perception' of the person who reports it. The argument by Schuster et al (2005) even though based on a study many years ago is still quite compelling – that is, that perceived discrimination still has the same consequences for the person who experiences it – that consequence is a negative impact on their health seeking behaviours and a continued distrust of the health system or parts thereof.

Seemingly simple matters might be self-reported by PLHIV as discrimination. Additionally given the above information about the consequences of perceived discrimination then clearly, based on information gathered through the case studies there still are incidences occurring which impact on PLHIV - and if they describe them as 'discrimination' then there should be an acceptance or understanding that they will impact on that person's health seeking behaviours anyway. Some examples worth noting from the case studies include:

- When a Doctor writes on the request to a pathology lab in large letters 'HIV Positive' – is that necessary documentation? Was the doctor being discriminatory?
- When a dialysis patient, who also happens to be HIV-positive is placed in another room for dialysis, another room separate to the other patients who are in for the day being treated for dialysis – is that necessary? Were the nurses being discriminatory?
- When a patient who is HIV-positive finds themselves regularly scheduled at the end of the day on the days list for minor procedures at the hospital e.g. biopsy – is that necessary? Is that a discriminatory practice that is occurring?
- When a patient is asked by a GP who they visited for the first time – 'how did you contract HIV' – is that an act of discrimination?
- When a patient in emergency care is approached by a doctor and the doctor says within hearing distance of other patients and ancillary staff 'so you're the person with HIV' – is that an act of discrimination?

The answers to the above questions would more than likely be considered as 'yes', certainly on the part of the HIV-positive person who is experiencing them. Whether they would be judged according to various pieces of discrimination legislation in different jurisdictions, or whether they would be understood by the health care staff themselves as acts of discrimination is a moot point. They are experienced by PLHIV as discrimination and such events are still occurring in Australia in 2016.

If, as identified in various reports published in Australia that PLHIV are now having more and different encounters across the health system with a broader range of specialists, generalists and in a variety of primary health care settings then another factor to consider is whether discrimination is being encountered in unexpected places. Indeed the case studies show that this is possibly the case. Not all health management issues for PLHIV are dealt with by S100 prescribers<sup>1</sup> – outside of the health system encounters with S100 prescribers there are reported incidents of discrimination in hospital settings by doctors and nurses. Again the case studies are only indicative but are a useful reference point, in that they point towards real incidents of discrimination that have been experienced. The case studies suggest that further work is required to ensure such incidents don't occur in the future.

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<sup>1</sup> Medical practitioners who prescribe antiretroviral medicine outside of a tertiary hospital HIV specialist unit

## SYSTEMIC BARRIERS IN THE HEALTH SYSTEM

Following a parliamentary inquiry on migration and disability in 2010, Australia made important reforms to its migration health assessment requirements and procedures. These included changes to the cost assessment related to health services for humanitarian visa applicants, and improvements to increase the transparency of the health assessment process – both matters which had impacted on PLHIV applying for entry to Australia. In March 2012 in Australia, DHHS ARV guidelines were changed to recommend ARV treatment for all PLHIV. In these two instances systemic barriers were removed. They were systematic because, generally without exception they were applying to all PLHIV within the system or who were encountering the system.

Systemic barriers are those which are inherent in the system. They are not random experiences but occur repeatedly - there is an element of predictability with regard to systemic barriers.

In terms of HIV care and treatment they are barriers which are generally known to persist over an extended period of time and usually can only be addressed through structural change or through legislative or policy interventions within the system.

Systemic barriers remain, and these may not all be specifically ‘within the health system’ or experienced at ‘the point of care’ but are relevant because stigma and discrimination are social processes which impact on PLHIV. The social experience or ‘life-world’ of HIV positive people is a significant determinant of their health seeking behaviours, if stigma and discrimination or fear of stigma and discrimination pervade the lifeworld of PLHIV then the desire to access care, treatment and support will be significantly reduced. These matters which might seem, in the first instance to be external to accessing HIV care and treatment are not – for PLHIV to be confident about accessing and sustaining HIV treatment in the long term they must also be confident in their experiences in the social world, their sexual lives and within the communities in which they live. Where systemic barriers continue to be encountered and encountered in the form of stigma or discrimination then individual confidence can be undermined and optimal health management may be undermined:

- Access to ARV for those people living in Australia who are ineligible for Medicare remains a systemic barrier. This represents unequal treatment within a system for one whole group of people – a clear example of discrimination.
- Changes to the delivery of HIV medications in NSW, now possible through community pharmacies is one example of a structural barrier being removed so that PLHIV have better access; despite this a recent report by Positive Life NSW (Community Dispensing Report 2016) has shown that in rural and remote areas concern about privacy and disclosure still remain. Fear of unwanted disclosure in some settings and for some PLHIV still disrupts the intention to provide better access.
- Women living with HIV have reported difficulty in meeting the costs of daily living, with half of those interviewed for *HIV Futures 6* living below the poverty line.
- Living below the poverty line is a systemic barrier to accessing appropriate health services within the health system, whilst this is an issue particularly for women, as above; it is worth noting that welfare support services for PLHIV generally may fall short of need. This cannot be uncoupled from stigma and discrimination generally – otherwise why is it that PLHIV remain uncertain about the treatment they will receive in other welfare services and prefer to access those already established for PLHIV? BGF are reported experiencing a 15% increase in demand in their last data collection period see ([http://www.bgf.org.au/bgf/images/assets/1580\\_bgf\\_strategicreport\\_art\\_web.pdf](http://www.bgf.org.au/bgf/images/assets/1580_bgf_strategicreport_art_web.pdf)) and HIVE South Australia (<http://positivelifesa.org.au/About%20us/The%20HIVE.html>) are still trying to keep their services going to provide basic food services and support for PLHIV.
- Laws that criminalise HIV non-disclosure, exposure and transmission perpetuate stigma and deter people from HIV testing, they also put the responsibility of HIV prevention solely on the person living with HIV. In May 2015, Victoria repealed the country’s only HIV-specific law criminalising the intentional transmission of HIV. However consistency of legislation across all jurisdictions in Australia

in relation to HIV disclosure has not been achieved. As an example, disclosure laws that still exist in New South Wales represent a systemic barrier within the system. Until there is a national framework that is consistently applied the 'criminalisation of HIV' remains a systemic barrier. PLHIV view these laws as discriminatory; this discrimination is not necessarily in the health system *per se* but certainly has the potential to impact PLHIV accessing services for health care and treatment. In Australia these laws have sometimes impeded a full and frank discussion between treating Doctors and some PLHIV about their sexual practices. These laws close down dialogue between Doctors and patients rather than opening up the space for full and frank discussions.

- Stigma, discrimination and fear of disclosure play out differently in for Aboriginal and Torres Strait Islanders and members of CALD communities. Higher rates of late diagnosis and later rates of taking up treatments indicate that there are still systemic barriers experienced by these groups in accessing HIV prevention, care and treatment services.

## ANNOTATED BIBLIOGRAPHY – PUBLISHED ARTICLES

### TITLE

Perspectives of People Living with HIV on Access to Health Care: Protocol for a Scoping Review

### AUTHOR

S. Asghari, A. Maaybank, O. Hurley et al.

### PUBLICATION DETAILS

Journal of Medical Internet Research Protocols. 2016 Apr-Jun; 5(2): e71.

### HYPERLINK IF AVAILABLE

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4889870/>

### KEY FINDINGS

- In developed countries, the number of PLHIV is increasing. With advances in HIV treatment and health care services, PLHIV are living longer, necessitating a wider range of preventive, acute, and long-term health care services to meet the needs of PLHIV across their lifetimes. The complexity of responses to meet the needs of PLHIV is heightened as HIV continues to disproportionately affect vulnerable populations.
- Access to health care is a complex concept that is usually measured according to multiple dimensions, including, expectations of health care providers or patients. But generally, in the past, the point of view of providers of services has been given the most credence.
- Recent studies emphasize that patients' perceptions of their access to health care services should be taken into account when implementing health programs. However, there is no unique consensus for patients' perspectives that can span all conditions and all populations.
- Consumer-perspective studies suggest visualizing issues through the eyes of the service users. These investigations include consumers' insights and *experiential* evidence of the totality of features of a product, and consumer-stated satisfaction (or their implied needs); and also should include recognition of consumer dissatisfaction and their identification of barriers to access.
- PLHIV's views on access to health care, which includes information about actual or perceived stigma need to be incorporated into research protocols which attempt to assess patient satisfaction and health services accessibility.

### RECOMMENDATIONS

This paper provides a unique research design and protocol arrangement which positions PLHIV centrally in terms of evaluating the sufficiency of health services provided to the population. The model of investigation outlined in this paper and the protocols proposed would be a valuable model to replicate as it places the patients perceptions at the centre of the project rather than relying solely on the view of health care providers. In doing studies which adopt the protocol outlined will provide a better way of understanding how stigma and discrimination (among other things) may impact on PLHIV access to care.

## TITLE

Barriers and Facilitators to HIV Testing in Migrants in High-Income Countries: A Systematic Review

## AUTHOR

Blondell, S.J., Kitter, B., Griffin, M.P. et al.

## PUBLICATION DETAILS

AIDS and Behavior. November 2015, Volume 19, Issue 11, pp. 2012-2024

## HYPERLINK IF AVAILABLE

Doi: 10.1007/s10461-015-1095-x

[HTTP://WWW.NCBI.NLM.NIH.GOV/PUBMED/26025193](http://www.ncbi.nlm.nih.gov/pubmed/26025193)

## FINDINGS

- Barriers were identified across individual, social and structural levels
- HIV testing and follow up treatment of migrants in high income countries has many complex dimensions

## RECOMMENDATIONS

Strong and empirical based information is required to deal with these issues noted above.

## TITLE

The impact of living with HIV: differences in experiences of stigma for heterosexual and homosexual people living with HIV in Australia

## AUTHOR

Loren Brener, Hannah Wilson, Sean Slavin and John de Wit

## PUBLICATION DETAILS

Sexual Health 10(4) pp. 316-319

## HYPERLINK IF AVAILABLE

<http://www.ncbi.nlm.nih.gov/pubmed/23680168>

## KEY FINDINGS

- Heterosexual PLHIV have a more negative experience in terms of both general HIV stigma but especially treatment-related stigma than gay PLHIV
- Due to stigma in their social environments they were less likely, in this study group, to access HIV care and treatment than gay PLHIV

## RECOMMENDATIONS

HIV-related stigma may account for the lower HIV treatment uptake in heterosexual PLHIV. Addressing treatment-related stigma could contribute to increasing access to HIV treatments for this population.

## TITLE

Enablers and barriers to the implementation of primary health care interventions for Indigenous people with chronic diseases: a systematic review.

## AUTHOR

O Gibson, K Lisy, C Davy, E Aromataris, E Kite, C Lockwood, D Riitano, K McBride, A Brown

## PUBLICATION DETAILS

Implementation Science 2015 **10:71**

## HYPERLINK IF AVAILABLE

DOI: [10.1186/s13012-015-0261-x](https://doi.org/10.1186/s13012-015-0261-x)

<http://www.healthinfolnet.ecu.edu.au/key-resources/bibliography?lid=29530>

## KEY FINDINGS

- Low quality or racist treatment afforded to some Indigenous patients continues to discourage people from accessing services.
- Research suggests that health care providers need to also understand health from the perspective of the patient, appreciate the importance of establishing long-term relationships with the community, provide an 'Indigenous space' where patients feel comfortable and cared for, and respect the strong ties that Indigenous people have to family and their land.
- The presence of Indigenous health workers and/or the provision of health care in Indigenous spaces create a friendly and relaxed atmosphere for patients. Indigenous Health Workers provide cultural safety for patients.
- There are peer influences based on traditional or cultural understanding that can either enable or inhibit access to care.
- Clients need to be able to consistently access services (i.e. ongoing service availability) and experience continuity of care.
- It is important to consider the role of the family when providing chronic disease care to Indigenous patients and when considering the patient's ability to manage their chronic disease.
- Providing a culturally safe service is an enabling factor for Indigenous patients accessing chronic disease management and must include treating patients and their families with respect and consideration.

## RECOMMENDATIONS

Findings from this review should be used in the successful design, implementation and sustainability of chronic disease interventions in health care settings intended for Indigenous people.

## TITLE

Adherence to antiretroviral therapy: factors independently associated with reported difficulty taking antiretroviral therapy in a national sample of HIV-positive Australians

## AUTHOR

J. Grierson, RL Koelmeyer, A Smith, M Pitts

## PUBLICATION DETAILS

HIV Medicine. 2011 Volume 12, Issue 9 pp. 562-569

## HYPERLINK IF AVAILABLE

DOI: 10.1111/J.1468-1293.2011.00928.x

<http://onlinelibrary.wiley.com/doi/10.1111/j.1468-1293.2011.00928.x/pdf>

## KEY FINDINGS

Factors found to be independently associated with reported difficulty taking ART included:

- younger age
- alcohol and party drug use
- poor or fair self-report health
- diagnosis of a mental health condition
- living in a regional centre
- taking more than one ART dose per day
- experiencing physical adverse events or health service discrimination
- experiencing health service discrimination was one of the 13 distinct variables independently associated with reported difficulty taking ART.

## RECOMMENDATIONS

The authors argue that the study is highly generalizable to the broader Australian population of PLHIV and HIV-positive men who have sex with men. The study implies that clinicians need to be aware of the extensive range of variables that have the potential to impact on the uptake and adherence to HIV treatments. In this range of variables health service discrimination is one of the factors that can increase the difficulty of taking ART.



## TITLE

HIV among Indigenous peoples: A Review of the Literature on HIV-Related Behaviour Since the Beginning of the Epidemic

## AUTHOR

Joel Negin, Clive Aspin, Thomas Gadsden, Charlotte Reading

## PUBLICATION DETAILS

AIDS and Behavior 2015; 19(9) 1720-1734

## HYPERLINK IF AVAILABLE

[HTTP://WWW.NCBI.NLM.NIH.GOV/PMC/ARTICLES/PMC4551545/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4551545/)

## KEY FINDINGS

- This population group experiences negative social and economic determinants including colonialism and racism that not only increases potential exposure to HIV and also impacts on treatments uptake and staying in care arrangements.
- Social disadvantages including high rates of unemployment, low educational achievement, and poor access to health services cannot be underestimated as impacting on health seeking behaviours.
- Mistrust of health services is common across this population group and treatment outcomes are generally poorer than the general population.
- The two most significant factors affecting HIV treatment adherence and outcomes were ongoing substance abuse and the timing of treatment uptake.
- Stigma and lack of confidentiality were identified as barriers to testing for Indigenous peoples.

## RECOMMENDATIONS

This highlights the need for greater cultural sensitivity and competency development among health care staff, care providers and health programs serving Indigenous communities. The mistrust of health services by Indigenous people is real and can be accounted for as based in the past experience of Indigenous populations. There are not only systemic barriers for access but also structural inertia and a lack of resources in responding to the particular of Indigenous people across the whole of the health system.

## TITLE

Facilitating HIV Disclosure Across Diverse Settings: A Review

## AUTHOR

Carla Makhouf Obermeyer, Parijat Baijal, Elizabetta Pegurri

## PUBLICATION DETAILS

American Journal of Public Health June 2011;101(6): pp.1011-1023

## HYPERLINK IF AVAILABLE

<http://www.ncbi.nlm.nih.gov/pubmed/21493947>

## KEY FINDINGS

- In high income countries disclosure tends to be higher.
- Individuals from racial/ethnic minority groups have greater concerns about stigmatisation.
- There are substantial gender differences in the contexts and confidence about disclosure with women being generally more concerned about unwanted disclosure occurring.
- Economic and social disadvantage make disclosure more difficult.
- Disclosure is often not voluntary, especially in family contexts which can lead to disrupted relationships and isolation - and also potentially disrupt uptake of ART
- Whilst some studies show a positive relationship between disclosure and social supports, a positive experience around disclosure cannot always be assumed.
- In Australian health facilities, more women than men reported fearing discrimination in the form of avoidance of treatment, extra precautions, and confidentiality problems.

## RECOMMENDATIONS

Few people keep their HIV status completely secret and in developed countries levels of disclosure are generally high. Health worker facilitation of disclosure was limited by the potential for discrimination at health facilities which implies that any sense of potential discrimination at health facilities must be removed. Research confirms the reciprocal connections among stigma, social support, disclosure and use of health service facilities.

## TITLE

Perceived Discrimination in Clinical Care in a Nationally Representative Sample of HIV-Infected Adults Receiving Health Care

## AUTHOR

M Schuster, R Collins, W Cunningham et al.

## PUBLICATION DETAILS

J Gen Intern Med. 2005 Sep; 20(9): 807–813.

## HYPERLINK IF AVAILABLE

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1490199/>

## KEY FINDINGS

- Some discriminatory acts are overt and easily identifiable such as derogatory comments; other form of discrimination are more subtle such as, providing less emotional support or less thorough care than usual.
- Discrimination against HIV positive people may be more complex than against people with other diseases – this is because HIV generally affects groups who are already stigmatized in the absence of infection and this includes gay men, bisexual men and people who inject drugs; there may also be racial/ethnic discrimination, also independent of HIV.
- HIV-infected people may experience discrimination because of their infection, another characteristic, or both.
- The sense of what constitutes discrimination is complex – for example a physician who refers a patient to someone with greater HIV expertise could be perceived by the HIV positive person as refusing care or not wanting to care for the HIV positive person.
- Perceived discrimination was less prevalent for people diagnosed more recently.

## RECOMMENDATIONS

Regardless of whether perceived discrimination indicates real bias, the perception of bias is important and can have consequences that interfere with health and health-promoting behaviours. A perception of discrimination causes distress and may discourage PLHIV from seeking further care or follow up. Educational programs and modelling of non-discriminatory behaviour may be able to reduce non-discriminatory behaviour and reduce overt acts rather than prejudiced attitudes. Effective strategies must be developed to reduce actual and perceived discrimination in health care settings.

## ANNOTATED BIBLIOGRAPHY – MONOGRAPHS, REPORTS, CONFERENCE PRESENTATIONS, INFORMATION/FACT SHEETS

### TITLE

HIV statistics in Australia: Women

### AUTHOR

Australian Federation of AIDS Organisations

### PUBLICATION DETAILS

First published on 22 November 2012 and reviewed on 13 October 2015

### HYPERLINK IF AVAILABLE

<https://www.afao.org.au/about-hiv/the-hiv-epidemic/hiv-statistics-australia/hiv-statistics-women-in-australia#.V6w27Ft96U>

### KEY FINDINGS

- Few women are diagnosed with newly acquired infection, compared to gay men and other men who have sex with men (MSM).
- Women are less likely to have an HIV test as part of routine health screening.
- Women living with HIV in Australia are a diverse group.
- Mental health conditions, predominantly depression, are experienced by a high percentage of HIV positive women.
- Women living with HIV may find it difficult to meet the costs of daily living and were more likely to use the financial assistance service provided by HIV services than HIV positive men.

### RECOMMENDATIONS

Given the above information is more than reasonable that women living with HIV report a sense of feeling stigmatised or discriminated against within the HIV response in Australia.

## TITLE

How does Stigma affect HIV prevention and treatment?

## AUTHOR

Centre for AIDS Prevention Studies and the AIDS Research Institute, University of California

## PUBLICATION DETAILS

May 2005 Fact Sheet 60E

## HYPERLINK IF AVAILABLE

<http://caps.ucsf.edu/archives/factsheets/stigma>

## KEY FINDINGS

- Stigma is expressed in a variety of ways including; rejection, avoidance, discrimination by health care professionals and communities, testing without prior informed consent, quarantining of persons with HIV or persons believed to be infected with HIV.
- Persons may not seek treatment or delay going to doctors due to real or perceived discrimination against them.
- Experiences of social rejection, disapproval and discrimination may decrease the motivation of HIV positive persons to seek treatment and be retained in health care.

## RECOMMENDATIONS

Stigma exists not just within individual actions but within broad social and cultural contexts that need to be addressed in stigma-reduction programs. HIV-positive persons must be involved in designing, running and evaluating stigma reduction programs.

## TITLE

HIV Populations in Australia: Implication for access to services and delivery

## AUTHOR

Marina Carman, Jeffrey Grierson, Michael Hurley, Marian Pitts and Jennifer Power

## PUBLICATION DETAILS

July 2009 Monograph Series Number 71, Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia

## HYPERLINK IF AVAILABLE

[https://www.latrobe.edu.au/arcshs/downloads/arcshs-research-publications/hiv\\_populations\\_australia\\_implications\\_access\\_delivery.pdf](https://www.latrobe.edu.au/arcshs/downloads/arcshs-research-publications/hiv_populations_australia_implications_access_delivery.pdf)

## KEY FINDINGS

- The HIV-positive population in Australia is growing. People living with HIV (PLHIV) are surviving longer and getting older on average.
- There is an increased emphasis on managing side effects and long-term toxicity, as well as co-morbidities related to ageing. The mental health demands of PLHIV are also emerging as significant.
- Two important emerging issues are potential changes in the patterns of geographic location of the HIV-positive population, and changes in how and what type/style of services are accessed or wanted.
- The key issue remains tailoring medical and other service delivery to individuals. This will require a balance between expanding access to mainstream services, and developing or supporting the capacity of HIV-specific services in particular areas.
- The increasing availability of ART and the simplification of treatment regimens have had a significant (good) impact on HIV disease management. However, managing side effects and long-term toxicity are ongoing and important concerns. With long-term treatment increasing, there is also more attention being paid to co-morbidities related to ageing.
- Across all area types, those in the outer suburbs were the least likely to visit an HIV GP for HIV-related medical care (27% compared with 52% for those residing in inner suburban areas). People in outer suburban, regional and rural areas were also more likely than those in the capital city/inner suburban areas to access specialist HIV care at a sexual health clinic. Those in inner suburban areas were more likely to have visited an HIV GP (66%) than an outpatient clinic (42%). People from the outer suburbs were more likely to have visited a HIV specialist at an outpatient clinic (47%) than a HIV GP (40%).
- These differences may be related to geographic accessibility of HIV GPs and specialists. However, it is also possible that people living with HIV in rural areas prefer to travel to regional centres or cities for all their medical treatment rather than see the local GP. This may be for reasons of confidentiality and/or to ensure quality of care.
- The mental health demands of PLHIV are increasingly significant. The prevalence of depression amongst HIV-infected individuals is generally higher than in un-infected. Major risk factors include an AIDS-defining illness, older age and social isolation. Mania, hypomania and psychosis also occur more frequently. Almost 20% of HIV-positive men included in the Positive Health study had consistently sought mental health services in the previous 12 months, and another 45% had sought some medical treatment or counselling for mental health problems.

## RECOMMENDATIONS

There are important areas of future research, as identified in the report

- There is a gap in the data relating to how often and at what intervals PLHIV utilise medical services. This would help to understand to what degree healthcare demands are regular or episodic – as well as how this may vary across sub-populations and geographical locations.
- There is also a particular need for attention to be paid to trends such as the ageing of the HIV-positive population in Australia – how this process is influencing the experience of living with HIV, as well as patterns of service use/demand. This is related to generational shifts which seem to be occurring in the social experience and cultural/community characteristics of the population of gay and homosexually-active men, and to the growing diversity of the HIV-positive population.
- None of the existing studies or datasets provide sufficient evidence concerning those people living with HIV who have complex needs. These will include people who face significant social and economic challenges. PLHIV who are in short term or sheltered housing, those who have significant mental health issues and those who have drug and alcohol dependencies will continue to require high levels of support and are clearly underrepresented in the current evidence base.

## TITLE

HIV treatment uptake among people living with HIV in Australia: health promotion and policy responses to reduce barrier to treatment uptake.

## AUTHOR

Keen P, Watson J

## PUBLICATION DETAILS

ASHM Conference Poster in 2012

## HYPERLINK IF AVAILABLE

[http://napwha.org.au/sites/default/files/1375\\_napwa\\_ashm\\_A4\\_poster\\_art2.pdf](http://napwha.org.au/sites/default/files/1375_napwa_ashm_A4_poster_art2.pdf)

## KEY FINDINGS

- Late initiation of ART compared to recommended guidelines continues to occur
- Barriers to HIV treatment initiation included psychosocial barriers such as fear of side effects and reluctance to initiate lifelong treatment. These barriers remain despite improved HIV treatments

## RECOMMENDATIONS

Future health promotion initiatives should address the reported concerns and attitudes among PLHIV regarding ART and the psychosocial risk factors of non-adherence. Doctor-patient dialogue should be encouraged and enhanced clinical discussions with patients by doctors can support better understandings of patient needs and priorities.

## TITLE

The Australian HIV Observational Database Temporary Residents Access Study (ATRAS)

## AUTHOR

Kirby Institute and NAPWHA – Contact Dr Kathy Petoumenos

## PUBLICATION DETAILS

March 2015

## HYPERLINK IF AVAILABLE

<http://kirby.unsw.edu.au/news/australian-hiv-observational-database-temporary-residents-access-study-atras-two-year-follow>

## KEY FINDINGS

- There are an estimated 464 HIV-positive temporary residents in care over the past year who are ineligible for Medicare. Although the exact number at any given time is not known.
- HIV-positive temporary resident not eligible for PBS subsidised medications are left to access treatment by ordering from overseas, compassionate access, clinical trials or paying the full Australian price.
- Interrupted supplies due to delayed post, no guarantees of quality of medicines create further difficulties for this group.
- If ordering from overseas patients might be restricted to selecting regimes that do not provide the same standard of care as a HIV-positive Australian resident would receive.
- Current arrangements for managing HIV positive patients' who are ineligible for Medicare varies by jurisdiction – the disparity in arrangements across jurisdictions represents significant inequity of care and access to treatment for those individuals.
- Although many patients have private health insurance as part of their visa requirements, health insurance companies in Australia do not cover the costs of antiretroviral drugs. Many non-Medicare patients are therefore disadvantaged by a range of national and commercial restrictions on drug availability.

## RECOMMENDATIONS

This is one of the obvious systemic barriers, clearly based on discrimination against a certain group of people. It is an example which shows that all people living with HIV in Australia are not able to access optimal HIV treatment and in this instance it is clear discrimination at a systemic level and must be remedied if Australia is to meet targets aimed for in the National HIV/AIDS Strategy.



## TITLE

The HIV Stigma Audit: Community Report

## AUTHOR

Sean Slavin, Loren Brener, Denton Callander, John de Wit

## PUBLICATION DETAILS

2012 NAPWHA

## HYPERLINK IF AVAILABLE

[http://napwha.org.au/files/napwa\\_stigma\\_audit\\_report.pdf](http://napwha.org.au/files/napwa_stigma_audit_report.pdf)

## KEY FINDINGS

- To measure stigma an internationally respected scale was used, which once analysed, showed a moderate experience of stigma among respondents. Some examples of the questions asked in the scale and people's responses were: 34% agreed with the statement 'I feel guilty because I have HIV'; 77% agreed with 'Telling someone I have HIV is risky'; 35% disagreed with 'I never feel ashamed of having HIV'; 42% agreed with 'I work hard to keep my HIV a secret'; 40% agreed with 'most people think that a person with HIV is disgusting'; and 40% agreed with 'I have been hurt by how people reacted to learning I have HIV'.
- 42% agreed with the statement 'If I go to an HIV clinic I am concerned that someone might see me'; 47% agreed with 'I avoid taking my meds in public'; 42% agreed with 'I worry that people might see me collect my meds from the pharmacy'; 64% agreed with 'I am concerned that if I have physical changes from HIV meds people will know I'm HIV-positive'; and 61% agreed with 'I worry that side effects can make my status apparent'.
- Characteristics of people who experienced greater amounts of stigma included that they were; more likely to be single, have a lower level of education, report noticeable symptoms of HIV and experience stress, depression or anxiety. People with less experience of stigma were more likely to be resilient, have good self-esteem, be satisfied with their health, have good quality of life and good social support and be more likely to engage in HIV community.

## RECOMMENDATIONS

Initiatives to build resilience among people living with HIV should be developed. Opportunities for promoting resilience should be explored and exploited in the current body of education work occurring in the community-based response to HIV. Anti-stigma work should avoid the idea that people with HIV are passive receptors of stigma or require sympathy. The national HIV strategy should evolve to promote a more complex idea of PLHIV quality of life. As HIV prevention strategies evolve they should be reviewed to assess their effects on PLHIV. Based on the evidence disclosure remains a highly fraught and a better understanding of how problems of disclosure inhibit the quality of life of PLHIV needs to be understood – legal requirements around disclosure is one of the more obvious problem areas that could be remedied through, for example, review of the NSW Public Health law – but there are other areas where disclosure or fear of disclosure impacts on PLHIV.

## PERSONAL ACCOUNTS OR RESULTS OF YOUR ENQUIRIES

The accounts of stigma and discrimination below were collected the last week of July 2016. After a call-out to the NAPWHA membership, the author of the report interviewed via telephone or face-to-face 17 people who wanted to provide their stories. All who wanted to be have been included, and, where a similar issue was discussed the stories were combined under one heading.

These are de-identified and where service organisations have been named they are also de-identified but can be recalled if necessary for further intervention and follow up from the interviews.

In some ways the accounts provided below could be treated as case studies, which are supportive of the arguments presented at the beginning of the report and then along with reference back to the literature contained in the annotated bibliography, lead to the recommendations at the end of the report.

The case studies could also be drawn out to use for educative purposes demonstrating that in 2016 stigma and discrimination is still experienced by PLHIV in accessing HIV prevention, care and treatments and then also at particular identifiable points in health care service settings.

## TITLE

Regional/rural and remote concerns

## AUTHOR OR SOURCE OF INFORMATION

Information provided to author by persons A and M

## COLLECTING AGENCY

NAPWHA

## DATE

Information collected end July 2016, describing incidents that had occurred in previous 12 months.

## KEY FINDINGS

- There is a difference in experience in treatment and health management in the city compared to regional NSW, this probably applies equally in other states.
- There is greater fear of being found out as someone who is HIV positive or being 'spotted' and this leads to greater sensitivity over documentation that is kept eg. "My local GP requested some bloods and on the paper work for the pathology service put information about my HIV status – I had to ask the GP to remove that as I didn't feel the information would be secure amongst staff at the pathology services staff!"
- There is greater fear about disclosure in ancillary health services in rural areas eg. "I want to disclose my HIV status to the local dentist so that he is aware of my oral health needs. But I don't want to do this because the dental technician is a mother of my neighbour and I am not confident that my information will be protected. I have a sense that within the local community, knowledge of my HIV status could become a talking point and that would have negative consequences. Additionally - I suspect that my fear around HIV disclosure is also about the real fear of homophobia in the area in which I live."

## RECOMMENDATIONS

As shown in the annotated bibliography perceived discrimination or fear of discriminatory acts impedes health seeking behaviours.

Professional development activities aimed at sensitising HCWs in regional, rural and remote areas of Australia to current HIV treatment and care expectations, as well as particular concerns that PLHIV might have around disclosure should be implemented.

NB – this might not apply to all areas but perhaps this could be accompanied by a mapping exercise which shows which areas are showing up as more problematic.

## TITLE

Discrimination by GPs in primary health care settings

## AUTHOR OR SOURCE OF INFORMATION

Information provided by persons C and J1.

## COLLECTING AGENCY

NAPWHA

## DATE

Information collected at end July 2016 describing incidents that had occurred in previous 12 months

## KEY FINDINGS

- In two different primary health care settings – one in Adelaide and one in South East Queensland informants talked about being pressured by a GP to explain how they contracted HIV. In both instances the informants said that they were attending a GP and the facility for reasons other than related to their HIV treatment.
- In one instance the person said back to the GP ‘You have not right to ask that question’ and terminated the consultation in the other instance the person continued with the consultation but said in the interview ‘I felt powerless, ashamed and did not go back for further treatment at that facility about that health issue’ – I deferred dealing with that health issue until I got to a city.

## RECOMMENDATIONS

Clearly not all GPs are sensitised to HIV patient care. Focussed work across all primary care points and GPs is required.

In both these instances the informants said that the GPs said the reason for asking the question was that “they were just generally curious”; however the impact on the HIV positive person was significant. Greater sensitisation to the needs of PLHIV attending primary health services needs to occur.

NAPWHA recommends this be done through renewed efforts in pre and post vocational training courses or through renewed efforts in HIV health care workforce development which will focus more broadly on GPs.

NB - These two informants used different strategies to manage the situation at the time. It’s hard to argue that resilience building for PLHIV would resolve this kind of experience of discrimination, perhaps resilience building for PLHIV to respond in such situations is needed but NAPWHA suggests that this is really a workforce development issue. That is it should be dealt with in GP training.

## TITLE

Mental health services – an issue in regional areas and in cities

## AUTHOR OR SOURCE OF INFORMATION

Information provided by sources A and J

## COLLECTING AGENCY

NAPWHA

## DATE

Material collected at July 2016, described events which had occurred in previous 12 months.

## KEY FINDINGS

- Access to good mental health services is a key factor for PLHIV, especially given the higher rates of depression experienced by this population and the developing understanding of the effects of HIV and neurocognitive disorders (HAND).
- In examples provided from different sources, one when referred to a country based psychologist and another when encountering a city based psychiatrist shows that not all professionals operating in the mental health area are familiar with recent development in HIV disease management.
- In both instances the health professional concerned showed very little understanding of what the person with HIV understood as their sexual health responsibilities, those persons having now been treated for a number of years and sustaining levels of undetectable viral load.
- In one instance the psychiatrist wrote a report saying that the person's most important responsibility was to continue to practice safe sex – when in fact that person had not been practicing unsafe sex. The assumption underlying such a report by a psychiatrist can only be described as stigmatising.
- In the other instance the psychologist simply did not current information on the management of HIV disease at this point in time.

## RECOMMENDATIONS

All health professionals, especially those working in the area of mental health need to be updated on the changed knowledge about HIV transmission in the era of TaSP. This goes to the “triple A Q test” – access, availability, affordability and quality of care and treatment. In this case access existed but quality did not.

NAPWHA recommends that work be followed up with the key professional bodies for psychologist and psychiatrists to check whether there has been consistent education for them in the area of HIV treatment and management, so that if they are treating a patient referred to them they are aware of current science and knowledge around HIV treatment and care.

## TITLE

Access to HIV medications for those who are Medicare Ineligible

## AUTHOR OR SOURCE OF INFORMATION

Information provided by T

## COLLECTING AGENCY

NAPWHA

## DATE

Material collected end July 2016 but described what had happened over a 2 year period.

## KEY FINDINGS

- T is international student and therefore ineligible for access to HIV medications through Medicare.
- However special arrangements have been made through a clinic and his access to HIV care depends on the one sexual health clinic for the whole of SE Qld which makes it very difficult for anyone from a rural area to access services.
- He has learnt that different rules apply in different states and it makes it very awkward, not only for him in terms of travel, but he realises how difficult it is for others in similar circumstances in other states and this seems unfair, contradictory and discriminatory.
- Because he is accessing treatment through a compassionate access scheme and needs to change medications soon, when it comes time to change medications he has/had a lot of anxiety. The move to the only other affordable or accessible drug will place him in a situation of taking a sub-optimal treatment. He is aware that sub-optimal treatments will mitigate against maintaining an undetectable viral load and so worries further, that in the era of TaSP he is not taking the right medication.
- English is not his first language and digesting all of the information about becoming HIV was most difficult. He says that like most international students he came to Australia with limited sexual health knowledge.
- Reluctance to test and therefore a late diagnosis have created further problems in managing his HIV disease.
- He says Doctors he has encountered have generally been supportive but the best support has come from Health Care Workers who have experience themselves in working in bicultural and multicultural settings. He says his current strongest support is from HIV positive peers through peer network programs.
- His HIV status was disclosed in a hospital setting outside of the city and he was loudly lectured to by nursing staff who focussed on telling him that he must not be having unprotected sex.

## RECOMMENDATIONS

There must be a resolution of the systemic discrimination that is faced by those people living in Australia who are HIV positive but who are Medicare ineligible.

HCWs need not only to be competent in working cross-culturally and this includes nursing staff working in regional and rural areas.

## TITLE

Unwanted disclosure in clinical settings is experienced as stigma and discrimination by PLHIV – this can occur in emergency settings and hospital wards in large city hospitals.

## AUTHOR OR SOURCE OF INFORMATION

Information provided by J2, C, P, A and J3

## COLLECTING AGENCY

NAPWHA

## DATE

Material collected July, 2016, incidents had occurred in previous eighteen months.

## KEY FINDINGS

Story from a large hospital in Brisbane

- After a psychotic experience in public, J2 had been in police custody for five hours – which was distressing to begin with. When being handed to nursing staff at the hospital he disclosed that he was an injecting drug user and had Hepatitis C and HIV. He was being treated for management of both conditions. He also provided the details of his treating doctor who worked out of the hospital to which he was admitted. Without consent or explanation the attending nurse and doctor proceeded to take bloods, even though J2 said that the information about his current viral loads, CD4 count etc...should be available within the hospital or through contact with his treating doctor. On taking his bloods even though he didn't want them to, J2 said there was no attempt to reassure or calm him, rather the treatment by the doctor and nurse continued to anger him. J2 said that he believed neither the nurse nor attending doctor seemed comfortable about dealing with someone who had HIV and furthermore that they spoke loudly in the emergency room about his HCV and HIV status.

Story from a large inner-city Sydney hospital

- C said he was hospitalised via an emergency ward because he had presented as not being able to breathe properly and it was established that was because of a serious lung infection. There was a change of shift soon after and a new registrar arrived who said very loudly "So you're the guy whose HIV positive". C believed that people in other beds nearby heard this and including administrative staff on the unit. C was diagnosed with PCP – he was isolated in his own room and staff wore protective equipment for 3 days. On the 4<sup>th</sup> day an overnight nurse who came to take blood pressure and was "gowned/masked and double gloved". Two nights later a nurse who wouldn't come into the room at all; "asked me from the doorway if I was ok". Afterwards C said he was moved to shared ward - something about marriage equality came on TV and a patient went into homophobic diatribe and the nurse on the ward supported what the patient in the bed next to him was saying. The day after C discharged himself from hospital because he didn't feel safe. Next day he got a call from someone on the ward, he said he thought it was the registrar who said that if I didn't come back in they would call the police. Afterward when C told his story to friends they said "Well that's not unusual I've had Drs and nurses talk at the end of my bed about my HIV status in hearing distance from other patients."

## Other information about large inner-city hospitals and health care clinics

- A said, “I have experienced a number of times being put last on the days list for minor biopsy and procedures eg. banded hernia and hemorrhoids treatment. I wondered if this was standard practice, why are HIV positive people schedule for such list at the end of the day - I have heard from other HIV positive people in Sydney that this occurs but I have never thought to ask why, thinking about it, the fact that this occurs does seem to me unnecessary and discriminatory.”
- J3 said that many HIV positive people had reported to the organisation that he works for in Melbourne that they have been placed on the end of the list or at the end of the day for day unit procedures. He said that this had occurred for a range of day procedures including colonoscopies and also at dental clinics.

## Story from a large Melbourne hospital

- P said that he was in hospital for an anal fistula operation. The worry about the operation was causing enough problems. He was being prepared for the operation and was visited by the registrar who had a number of trainees with him, one of the trainee Doctors asked him aloud “By the way, how did you contract HIV?” A member of a family visiting the patient next door then stopped the registrar and asked if “Is this the AIDS ward?” P said he felt this was inappropriate and shouldn’t have occurred and it made him feel “vulnerable”.

## Story from another large Melbourne hospital

- P attended the hospital for dialysis. He was placed in an area away from all the others who were receiving dialysis that day. He said he did not understand why he was being isolated. He asked the nursing staff why he had been moved into a separate area. He was told “because you are tall and your feet will stick out and other people might bump into you.” P felt that this was not the real reason but was given to him as an excuse. P felt that the real reason he was in a separate room was more likely a decision that one of the staff had made because of his HIV status. P never returned to that hospital for treatment.

## RECOMMENDATIONS

Incidents like this can be devastating – behind each of these incidents reported above there is a complicated process of stigma and/or outright discrimination occurring. Whether it is called stigma or discrimination it doesn’t really matter.

It is of no consequence whether the patient could be considered to be oversensitive or maybe hypersensitive due to the circumstances in which they find themselves – it seems in all the above instances the HIV positive person has been treated very badly in a health care facility by health care staff who should know better.

How is it possible that in large inner city hospitals this can still happen?

Either sensitisation training needs to occur at these specific sites – as has probably occurred in the past/and/or pre and post vocational training for doctors and nurses generally needs to be revisited to understand whether HIV patient care and management is being dealt with effectively in courses, curricula and training.



## TITLE

HIV positive workers in health care settings – dilemmas and resolutions.

## AUTHOR OR SOURCE OF INFORMATION

Information provided by B and D

## COLLECTING AGENCY

NAPWHA

## DATE

Information collected 2016 but also refers to historical material.

## KEY FINDINGS

- Throughout Australia Health Care Workers (HCWs) do not have to disclose their HIV status unless they are involved in exposure prone procedures. There is a long history of different aspects to this in Australia and from many different angles in relation to stigma, discrimination and disclosure. B and D both report that their experiences working in clinical and HIV service settings have generally been supported by management in the positions in which they have worked, but both explored some of the complexities and challenges that are faced, especially in terms of disclosure.
- Both B and D suggest that the treatment of HIV positive HCWs in clinical settings is a 'litmus test' or a 'surrogate marker' for how any particular health care services can ensure that they are genuinely places that would be free of stigma and discrimination against HIV positive people.
- For B who had a public profile in his local area about his HIV status, his dilemma in the workplace context was how he would be viewed by patients or other staff members when they found out his HIV positive status through his public disclosures. When this dilemma arose he consulted with his line manager, he provided reassurance that he did not have to disclose to other staff members and would be protected if any other workers or patients came to management about this matter. For B when this matter arose again, in another place, with another line manager, the issue was resolved but it wasn't clear within the organisational procedures or human resource information of the organisation how it was that the line manager should deal with this information.
- For D his public HIV status was seen to be an asset in terms of what he would contribute to a service that worked with HIV positive clients and patients. D has recently been in a dilemma about whether he should list his HIV illness/status on an application form applying for promotion – he feels he would like to make this disclosure so that is 'on the record' but feels it may jeopardise his promotion chances.
- For both B and D they have said that the journey of being a HIV positive HCW working in clinical settings has been a complicated journey, and that, despite being strong advocates and clear about their rights in these settings there has, at times been a sense of unease about how that might play out in particular contexts or situations or where there were not line managers who understood the nuance of the situation.

## RECOMMENDATIONS

Special attention needs to be paid to the dynamics of HIV positive HCWs who are employed in clinical and HIV service settings and resolving any dilemmas arising. This could be a useful project which will expose more nuanced understanding of how stigma, discrimination and the vexed area of disclosure can be managed in clinical and health care settings, and perhaps other work settings.

## TITLE

Women from CALD backgrounds have particular needs – and are sensitive to layers of stigma that might not be sensed by workers in health care facilities.

## AUTHOR OR SOURCE OF INFORMATION

Melbourne women from a CALD background via her friend.

## COLLECTING AGENCY

NAPWHA

## DATE

End July, 2016.

## KEY FINDINGS

- K received her HIV diagnosis off a GP in a private practice in outer Melbourne. K felt that the Doctor had little information and instead of worrying about herself she started feeling sorry for the Doctor and felt embarrassed for him that he was nervous with her. He then referred then referred her to an inner-city hospital and infectious diseases unit for clinical support.
- K was happy with that eventually, but it took a while for Doctors at the clinic she was now attending to identify some of her broader health management issues which were there other than the HIV management e.g. an IUD contraceptive device that was needing replacement wasn't attended to for a number of months. She felt that she could not raise this issue with the Doctors or they would make assumptions about what she was doing in her sexual life. K feared that they would be judgemental of her so she did not raise this immediately or within the first few consultations.
- K said that another matter that bothered her was the assumption that CALD communities will want to be all treated in one place. This is a real problem in the community to which K belongs because there is great fear of being discovered or exposed as HIV positive in that particular CALD community.

## RECOMMENDATIONS

Further research is required for this specific population group; stigma, discrimination and the complicated nature of disclosure in some CALD communities is not well understood, even though there has been research conducted in Australia on the barriers to accessing services for CALD communities practical strategies to address problems have still not been put into place.

Reluctance to test and late diagnosis occurring in particular CALD communities is evidence that fear, stigma and fear of discrimination, including enacted discrimination still plays a significant part in the lives of this population of PLHIV.

## TITLE

Heterosexual and bisexual men who are HIV positive – special concerns around stigma and discrimination.

## AUTHOR OR SOURCE OF INFORMATION

J3 and P

## COLLECTING AGENCY

NAPWHA

## DATE

End July, 2016 but reflections are over a period time.

## KEY FINDINGS

- J 3 said that HIV positive heterosexual men are confronted by the ageing process as well and there is fear that aged care facilities will not be able to accommodate their needs; nor will health care workers in such facilities understand that all HIV positive are not necessarily gay. HIV positive aging gay men might find a place in facilities that are specifically for gay men and staff trained accordingly but what is the future for HIV positive heterosexual men? There is fear of potential discrimination.
- Health professional networks need to be updated on the nature of the epidemic in Australia, there is a larger percentage now of HIV positive heterosexuals and public campaigns do not always reflect this reality, so when it comes to the interface with health care professional they still make assumptions about sexuality, identity and sexual practices. This mitigates against people engaging and staying engaged in care and treatment programs.
- P said that bisexual men have difficulty find a secure place in community settings. Often they are not welcomed in HIV heterosexual community programs and sometimes viewed with suspicion in gay community settings. The interface with sexual health professionals and with GPs and counselling support services is good but often the experience in these settings is also that HIV positive bisexual men are treated in terms of 'risk' rather than in terms of supporting their health management – a certain level of stigma is felt or perceived.
- An HIV positive heterosexual received his diagnosis after he asked to be tested by a GP the GP said "you're not gay are you – why would you want this? " The informant said that this indicated the GP was not aware of the realities of potential routes of HIV transmission.

## RECOMMENDATIONS

HCWs need to be regularly updated about epidemic patterns and a systematic campaign of the education of through professional health networks should be undertaken so that men living heterosexually with HIV and bisexual men do not feel discriminated against.

## TITLE

Access to prevention strategies

## AUTHOR OR SOURCE OF INFORMATION

C from Melbourne

## COLLECTING AGENCY

NAPWHA

## DATE

End July, 2016

## KEY FINDINGS

C said "One of the topics that sticks out to me is about being able to access prevention strategies. Are services going to be geared up to provide support? Some C's peer networks have had negative experiences and C went on to say:

- I am forthright so I was able to get to the outcome I wanted in the service, I avoided GPs in a particular clinic in Melbourne, some were pro-PrEP and other GPs in the practice did not have a good attitude. My not wanting to use condoms was questioned – with one GP telling me I had no right to be 'promiscuous'. This could easily deter people from seeking the new prevention technologies.
- Some GP's have gone through training eg. In metropolitan areas but what about regional and rural areas. What hope does anyone in country areas have for accessing PrEP ?
- C said, "Stigma is anything that constitutes anybody else creating a negative moral judgement around other people's behaviour and then communicating that". He said that unfortunately, through his peer networks he knew of instances where this has occurred. Stigma leads to shame, which is then internalised and individuals don't then pursue health seeking behaviours.
- C said, "Coming in from PrEP angle is important – clinical guidelines have been produced by ASHM – but are these guidelines understood by all health care professionals."
- C said, having feelings of being disempowered or not being able to access new prevention technologies without being judged by Doctors is no way to enter this new phase of TaSP unfortunately "social care shaming" occurs.
- C said, "We don't want social peer shaming to merge into social care shaming and we don't want that sense of judgement from that Doctors who we respect."

## RECOMMENDATIONS

Better pre-service training in all professional areas eg. GPs, nursing, specialists, psychiatrists and psychologists.

All health care professionals need to be updated on TaSP era and the possibilities of the use of PrEP in managing the epidemic.

## TITLE

Stigma and discrimination in health care settings is still experienced in smaller states and territories.

## AUTHOR OR SOURCE OF INFORMATION

T from Tasmania and N from Darwin

## COLLECTING AGENCY

NAPWHA

## DATE

End July, 2016

## KEY FINDINGS

- T from Tasmania reported that some people are not accessing services in Tasmania but those in the north-west are going to Victoria for treatment.
- Some fear using Launceston hospital and becoming known as someone with HIV.
- There is fear of going to local, unknown GPs.
- Dr Louise Owen running the sexual health clinic in Hobart is trying to get more GPs involved and some to pick up their skills in s100 prescribing and her work is appreciated but there are still difficulties.
- N encountered a judgement approach about injecting drug use in a clinical setting; C did not return to that clinic for treatment but opted for another point of care for their HIV care and management. They went to another state for their care rather than continue to be treated in Darwin.

## RECOMMENDATIONS

Some states and territories with smaller populations of PLHIV need particular attention. HIV positive peer links in South Australia are at risk after defunding of services and this reduces the ability of HIV positive people to talk with each other about what they are experiencing in health care settings.

## CONCLUSIONS

This submission contains evidence that stigma and discrimination is still being experienced by PLHIV in accessing health services. Some systemic barriers in accessing HIV prevention, care or treatment have been noted. NAPWHA suggests that if these continue then it undermines the targets outlined in various strategy documents and is concerned that unless these barriers are removed then the hope that is offered under the current model of TaSP is at risk. Not everything can be remedied through personal PLHIV empowerment models, most of the recommendations on the previous pages have workforce development implications and these need to be followed up by ASHM and through other professional bodies and association where relevant. Pre and post vocational training and the curricula that are being used to train new health professionals needs to be reviewed, to ensure that 'HIV is still on the agenda', and that those coming into the workforce are equipped with up to date knowledge.

The understanding of how stigma and discrimination experienced in the social sphere and life-worlds of PLHIV impacts on treatments uptake and accessing of services, by those who are diagnosed as HIV positive, is still something not well understood and needs further exploration. PLHIV themselves are best positioned to articulate this relationship and work in that area needs to be supported. The importance of the last statement is underscored by the fact that not all people in Australian who have tested positive for HIV are accessing ART, despite current guidelines recommending that they do so. There will be a problem achieving targets unless those people do commence ART – there is a sense that the persistence of stigma and discrimination may provide some understanding of why there is not consistent uptake of ART across Australia.

Recommendations outlined in the previous section are reworked here in a briefer format.

## STIGMA

Not all health professionals seem to understand that a HIV positive person, on optimal treatment regime, can have an undetectable viral load and therefore is not an infectious health risk in sexual or health care contexts anymore.

### HEALTH SERVICE IN WHICH THIS IS EXPERIENCED

Stigmatising attitudes have been described as occurring in a number of health service facilities and contexts.

### YOUR RECOMMENDED REMEDIATION

Places identified in this report where stigmatising attitudes were encountered should be contacted for follow up and where necessary education activities for staff should be planned. NAPWHA or relevant state based organisations of PLHIV should be engaged in these education activities putting forward the perspective of PLHIV.

## STIGMA

Fear of disclosing ones HIV status is a sign that an HIV positive person fears being stigmatised.

### HEALTH SERVICE IN WHICH THIS IS EXPERIENCED

A number of informants have described the geographical areas in which they experience such fear.

### YOUR RECOMMENDED REMEDIATION

A mapping of the geographical areas in Australia where people have this fear should be undertaken and then targeted work should continue in those areas with health professionals so that HIV positive people living in those places can be confident about attending HIV friendly clinical environments. NAPWHA or relevant state based organisations of PLHIV should then be engaged in these education activities putting forward the perspective of PLHIV.

## STIGMA

Particular sub populations of PLHIV have greater concerns that they will be stigmatised.

### HEALTH SERVICE IN WHICH THIS IS EXPERIENCED

As described in the case studies this can occur in any setting – see for example concern from a women from a CALD background and people living heterosexually with HIV and bisexual men.

### YOUR RECOMMENDED REMEDIATION

A key reference in the annotated bibliography suggests that further empirical work is required to understand the dynamics for example, migrants in High-income countries like Australia. There should be ongoing studies involving CALD communities and other sub population groups to understand the dynamics of how stigma is impacting on access to HIV treatment care and support.





## DISCRIMINATION

Being isolated in a health facility without explanation or mistreated in a health facility without explanation.

### HEALTH SERVICE IN WHICH THIS IS EXPERIENCED

This has occurred in large hospitals in Melbourne and Sydney

### YOUR RECOMMENDED REMEDIATION

Those facilities should be approached with the case studies provided in this report and be prepared to offer some explanation or be prepared to initiate some HIV care awareness raising activities where relevant. NAPWHA or the relevant state based PLHIV organisations should be involved in any of these awareness raising activities putting forward the perspective of PLHIV around this issue.

## DISCRIMINATION

A HIV positive person having their status disclosed when this is not necessary or without their consent.

### HEALTH SERVICE IN WHICH THIS IS EXPERIENCED

A number of examples of this occurring in particular facilities are described earlier in this report.

### YOUR RECOMMENDED REMEDIATION

Those facilities should be approached with the case studies provided in this report and be prepared to offer some explanation or be prepared to initiate some HIV care awareness raising activities where relevant. NAPWHA or the relevant state based PLHIV organisations should be involved in any of these awareness raising activities putting forward the perspective of PLHIV around this issue

## DISCRIMINATION

Real or perceived discrimination has been experienced by sub populations, including people who inject drugs and women.

### HEALTH SERVICE IN WHICH THIS IS EXPERIENCED

This seems to be a more generalised experience of discrimination of potential discrimination.

### YOUR RECOMMENDED REMEDIATION

HCW training programs and pre and post vocational training programs need to be assessed to see whether there is substantial enough content to ensure that graduating health care professionals are aware of how particular sub populations may experience discrimination and sensitivity training around these issues needs to occur on an ongoing basis.

## SYSTEMIC HEALTH SYSTEM BARRIERS

Access to ARV for those who are Medicare ineligible.

### HEALTH SERVICE IN WHICH THIS IS EXPERIENCED

Across Australia and in all jurisdictions.

### YOUR RECOMMENDED REMEDIATION

This matter needs to be resolved as a matter of urgency.

## SYSTEMIC HEALTH SYSTEM BARRIERS

Higher rates of late diagnosis and later uptake of ART is observable and reported in particular sub-populations of PLHIV.

### HEALTH SERVICE IN WHICH THIS IS EXPERIENCED

This occurs across Australia.

### YOUR RECOMMENDED REMEDIATION

Why this occurs requires specific research and investigation and should be undertaken as partnership work within the national HIV strategy.

## SYSTEMIC HEALTH SYSTEM BARRIERS

The health system is not isolated from the social/welfare systems or legal systems.

### HEALTH SERVICE IN WHICH THIS IS EXPERIENCED

In this report poverty and laws that criminalise HIV non-disclosure have been referred to as systemic barriers because for some they are encountered as problematic and systematically problematic. The ability and willingness of people to engage with health care providers is often compromised by barriers outside of the health system but are played out inside the health system.

### YOUR RECOMMENDED REMEDIATION

ASHM and partner organisations should resolve whether these can be addressed further within their various remits.

# NAPWHA

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