

HEPATITIS C MODELS OF ACCESS AND SERVICE DELIVERY FOR PEOPLE WITH A HISTORY OF INJECTING DRUG USE

Australian Injecting and Illicit Drug Users League (AIVL) // October 2010





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1 Executive Summary

Research evidence reflects that in Australia unsafe injecting practices account for almost 80 percent of all current hepatitis C infections and over 90 percent of all new infections (Razali, 2007). While this evidence highlights the importance of focusing on strategies to prevent the further transmission of hepatitis C among people who inject drugs, the high rates of current infection also emphasise the urgent need to focus on the development of appropriate models of access and service delivery for people with hepatitis C and a history of injecting drug use. The need for more appropriate and targeted models of access and service delivery is further highlighted by the fact that 75 percent of people infected with hepatitis C will develop chronic infection (NCHECR, 2009a).

Unfortunately however, other than the broad estimates and projections outlined above, we know very little about the social and geographical profile and needs of people with chronic hepatitis C in Australia particularly those with a history of injecting drug use. Research and surveillance tell us little about the geographical location of people with chronic hepatitis C infection or how this relates to the demand for or availability of clinical and non-clinical services for this group. There is a need to map the patterns of geographic location for the population of people with chronic hepatitis C particularly in relation to whether people are located in urban, regional or rural areas. There is also a need to better understand the type of services that are being accessed or are required including peer support and non-clinical services particularly for groups that experience more socio-economic disadvantage such as Aboriginal & Torres Strait Islander people and people from CALD backgrounds who also have a history of injecting drug use.

Recent estimates show, in 2005 there were upwards of 80,000 opioid dependent injecting drug users in Australia with almost 40,000 of those people accessing some form of pharmacotherapy (methadone, buprenorphine and buprenorphine/naloxone) maintenance programs (AIHW, 2009). With almost half of all dependent opioid users on methadone or buprenorphine, pharmacotherapy remains the most accessed form of drug treatment in Australia. In this regard, pharmacotherapy settings can represent a unique opportunity for providing an integrated and

supportive approach to hepatitis C treatment and management for some people with chronic hepatitis C infection. Having said this however, while there is an urgent need for alternatives to only providing hepatitis C treatment through specialist liver clinics in major public hospitals, it is very important that opioid pharmacotherapy settings are not seen as the 'panacea' or the complete solution to fixing the problem of the low number of hepatitis C treatment episodes among those most affected by hepatitis C.

For many people living with chronic hepatitis C infection, the standard treatment models for both hepatitis C and drug dependency can be intimidating, frightening and difficult to access. Research into drug treatment accessibility has found that:

“while illicit drug users have many health problems, they often view orthodox medical services as forbidding, judgmental, inaccessible, costly or otherwise inappropriate for their needs” (Treloar, 2004).

The landmark *C-Change Report* into hepatitis C related discrimination produced by the NSW Anti-Discrimination Board also highlighted the sad fact that, hepatitis C related stigma and discrimination is rife within the health system (NSW ADB, 2001). AIVL believes it is this type of systemic and entrenched stigma and discrimination that provides a large part of the explanation for why there are extremely low levels of hepatitis C treatment uptake among people with a history of injecting drug use. While the precise levels of treatment uptake among people with a history of injecting drug use is not well monitored, the extent of the problem was highlighted in the *2006 Hepatitis C Estimates and Projections Report* which stated only 1 percent of people attending Needle & Syringe Programs reported receiving combination treatment for hepatitis C infection (NCHECR, 2006).

In this context of routine discrimination, poor access to primary health care and social, legal and economic marginalisation it is extremely important that the solution to low treatment numbers is not seen as simply transferring people from one part of the health system to another – that is from hospital based liver clinics to

hospital or community-based pharmacotherapy clinics. In the discussions about increasing the availability of hepatitis C treatment in pharmacotherapy settings there has been insufficient discussion and planning about the ethical and resourcing implications of creating an increased demand for hepatitis C treatment in a setting (pharmacotherapy programs) where there are well-documented problems with the quality of care and inadequate resources to deliver core programs effectively, let alone enhanced service models (AIVL, 2008b & 2010b, Treloar and Holt, 2006, Treloar, 2004, Holt, 2007).

While there is evidence to support the fact that some people like the 'one-stop shop' convenience of offering hepatitis C management and treatment in pharmacotherapy settings (Treloar, 2010b), there is also a need to recognise that not all people will want to receive treatment for or management of their hepatitis C through their pharmacotherapy prescriber/clinic. There are many good reasons why some people may wish to keep these aspects of their health care separated not the least of which relates to the capacity for people to be honest in relation to their hepatitis C treatment and ongoing drug use when such honesty is likely to have a negative impact on their pharmacotherapy arrangements (Aitkin, 2002). The poor access that opioid pharmacotherapy clients have to pain management and symptomatic relief for acute and chronic conditions (Morgan, 2006) is another reason why people may not be willing to undergo hepatitis C treatment and management in the pharmacotherapy setting. For these reasons there needs to be a range of models of access and service delivery for hepatitis C.

While AIVL welcomes efforts to increase access to safe, effective and appropriate health services for people with a history of injecting drug use, we are genuinely concerned about what appears to be a disproportionate focus on 'quantity' (increasing treatment episodes) rather than 'quality' (addressing some of the core reasons why there is a need to set increased treatment targets in the first place). It is in the interest of exploring and encouraging further discussion on the reasons why people with a history of injecting drug use are not accessing hepatitis C treatment and what can be done about this situation, that AIVL has developed this national discussion paper on models of access and service delivery. In developing this paper, we do discuss the role of pharmacotherapy services in hepatitis C treatment as this will be an appropriate setting for some people, but we have also attempted to identify some of the other issues and approaches that must be addressed if we wish to provide appropriate and effective treatment and care for those most affected by hepatitis C.

Some of these approaches are already under discussion and/or under-development at the national and jurisdictional levels including better utilisation of GP and

nurse-led models and how to enhance the acceptability and accessibility of current specialist-based liver clinics. Throughout this document, AIVL recognises the important work already underway to improve models of treatment and management for hepatitis C and where possible we have attempted to value-add to current thinking and practice. One of our main contributions to this dialogue is our examination in this paper of some of the main barriers to existing and developing models of access and service delivery for people with hepatitis C and a history of injecting drug use. In outlining these key barriers to access for our community, we have also attempted to provide recommendations on strategies that may be effective in addressing these problems. In particular, as an organisation with significant expertise on IDU peer support and consumer advocacy, we have included a major focus on the central role of peer support and advocacy within enhanced and intergrated models of access and service delivery for hepatitis C.

The other important aspect of the document is the recognition that "models of access and service delivery" does not mean "models of treatment" or clinical models alone but rather should be focused on the broad range of care and support needs for people with hepatitis C. This includes addressing barriers to access and service delivery across the entire prevention/care continuum. It also means needing to focus on and respond to the overarching systemic and structural barriers to access and service delivery for people with a history of injecting drug use. Such an approach requires integrated models of access and service delivery for hepatitis C which include broader health, social and lifestyle issues such as poverty, housing, criminalisation, mental health, stigma and discrimination, illegality, etc. Although the above represent some of the most challenging issues facing the public health system, they must be addressed if we hope to increase access to comprehensive and co-ordinated hepatitis C-related care for people with a history of injecting drug use.

This paper represents an important statement from the AIVL national network on the issues associated with access to hepatitis C services for people with a history of injecting drug use. If there is a primary aim of this paper it is to encourage thinking and discussion on the need for a fundamental process of reform in relation to the entire way we approach hepatitis C prevention, diagnosis, treatment and care. AIVL believes a community dialogue on why people with a history of injecting drug use are so disproportionately affected by hepatitis C is well overdue. We believe we can no longer simply focus on the development of new clinical models and creating more treatment places with out a frank acknowledgement of the impact of systemic violence and structural inequalities on the health of people with a history of injecting drug use including stigma and discrimination and the impact of illegality and criminalisation.

From the outset we acknowledge it is a large and wide-ranging paper, but we believe this was necessary to adequately capture both the big ideas and the specific detail that we must map out if we intend to really address the reasons why hepatitis C infections are so high and treatment rates are so low among our community. We do not under-estimate the challenges inherent within the ‘big ideas’ but equally do not believe that we can afford, at the societal level, to step back from these challenges. Given its length, and to assist readers in exploring the paper more easily it has been divided into a number of specific sections that can be read as stand alone texts but which have also been written with an ultimate overarching intention. We strongly encourage people to read the entire document as it represents a strategic overview of barriers and access issues for people with a history of injecting drug use. In saying that, we also recognise that people will have particular areas of interest and focus and in this regard, each section provides an identification and assessment of key issues and barriers and recommendations for addressing them.

The three main sections within the paper take you through the key components of a systemic overhaul of hepatitis C access and service delivery for people with a history of injecting drug use including:

1. **Introduction** – this section provides a brief background to existing approaches to hepatitis C models of access and care and why there is a need to review these approaches. It also includes an explanation of why AIVL has chosen to use the term “people with a history of injecting drug use” throughout the paper and the significance of this terminology in relation to hepatitis C.
2. **Models of Access & Service Delivery** – this section provides an overview of the key models that need to underpin a comprehensive, integrated and responsive approach to hepatitis C among people with a history of injecting drug use. The models explored include primary health care approaches, chronic disease management strategies and peer-based education and support. The section concludes with an examination of the current process of health system reform and how this might impact on and provide opportunities for the introduction of new models of access and service delivery for hepatitis C.
3. **Barriers to Access & Service Delivery** – this final section is the largest in the document as it includes a detailed examination of the social and structural factors that affect the ability of people with a history of injecting drug use to address their health and access services. The three key issues explored in this section include:
 - i. **Systemic Barriers to Hepatitis C Access & Service Delivery:** this sub-section commences with an examination of the impact of stigma and discrimination and of illegality and criminalisation on people’s health and wellbeing. The assessment of these structural factors is followed by an exploration of recommendations on how to address these systemic barriers to hepatitis C access and service delivery for people with a history of injecting drug use.
 - ii. **Environmental Barriers within Existing Hepatitis C Services:** this sub-section seeks to identify and address some of the more practical or environmental barriers to access and service delivery for people with a history of injecting drug use. This includes an assessment of existing hepatitis C services in primary prevention, testing and diagnosis and tertiary care such as liver clinics, GP shared care arrangements and hepatitis C treatment in opioid pharmacotherapy settings. Recommendations are provided for addressing barriers to access and service delivery in each of these settings.
 - iii. **Others Issues & Barriers to Hepatitis C Access & Service Delivery:** this final sub-section concludes with a brief overview of other issues and factors that can prevent access to existing hepatitis C services for people with a history of injecting drug use including housing, home care support, Centrelink and income support, post treatment care and self-management strategies. Once again, a series of recommendations are provided for addressing barriers to access and service delivery in relation to each of these issues.

AIVL believes this paper is essential reading for people across the entire hepatitis C partnership approach. It is ambitious and attempts for the first time to articulate in some detail what it is like to experience the health system as a person with hepatitis C and a history of injecting drug use. Indeed much of the detail and expansiveness in this paper is due to our desire to provide a document that is about more than structures, systems and approaches but importantly, how those mechanisms impact on the lives of people affected by hepatitis C. We believe this paper stands apart from other ‘models of care’ documents in that it brings the voice and experience of people directly affected by hepatitis C from the margins to the centre. The illegality and process of criminalisation associated with injecting illicit drugs pushes people underground and away from services, family, friends and support. For this reason, it is essential that organisations such as AIVL raise awareness among service providers,

policy makers, researchers and others of the experiences of people who have been marginalised and excluded due to their involvement in injecting drug use.

This paper calls for change at the macro and micro levels in relation to the way we currently approach hepatitis C prevention, diagnosis, treatment and care for people with a history of injecting drug use. As appropriate we have attempted to provide concrete recommendations in each of the sections above on how we can commence the process of creating a response to hepatitis C that is appropriate and acceptable to those who are living with the condition. As stated above, AIVL acknowledges the important and high quality services and work that are already underway in relation to hepatitis C. This paper does not seek to deny this work, in fact we hope we have highlighted areas of good practice as appropriate. But areas of good practice do not mean that we have thought enough, done enough, to secure a foundation for our response to hepatitis C that ensures that even the most marginalised can get access to services and care they need when and how they need it. This is the fundamental challenge this paper seeks to address. We hope it achieves this purpose and we hope it leads to a complete review of the current approach to hepatitis C among people with a history of injecting drug use. ■

2 Introduction

In July 2003, a document entitled *A Model of Care for the Management of Hepatitis C Infection in Adults* was published by the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD). This paper sought to provide “best practice guidelines for the clinical care of people with hepatitis C”. It states that “effective management of individuals undergoing screening and/or treatment for hepatitis C requires medical practitioners and clients to develop a partnership approach based on open communication, trust, shared decision making and information exchange”. The document goes further to outline some of the key aspects of such a partnership approach and states that:

“A partnership approach between medical practitioners and clients involves:

- *Taking a holistic approach (treating the client as a whole person, with many potential interacting issues rather than as a person with one disease.*
- *Non-judgemental and respectful attitude towards clients’ needs, treatment preferences and lifestyle.*
- *Providing advice and information on the full range of medical and non-medical approaches to managing hepatitis C.*
- *Empowering clients with sufficient information to make informed decisions that best suit their lifestyle, occupational and social responsibilities, personal needs and preferences.*
- *Developing rapport and mutual trust.” (ANCAHRD, 2003)*

The principles outlined above are relevant and consistent with accepted models of primary health care and chronic care management and, as such, AIVL agrees in a broad sense with these statements and goals. The problem however with the current model of care is that it is limited both in terms of its reach and in relation to what it defines as a “model of treatment and care”. For example, the current model does not encompass strategies to support people with hepatitis C who are not undergoing treatment and/or not planning to undergo treatment in the short to medium term and who are at different stages of their personal journey with hepatitis C.

The current approach also does not provide adequate focus on the needs of people who have undergone treatment and have either cleared or not cleared the virus but whom have a range of post-treatment health and support needs that should be addressed by a comprehensive model of access and service delivery for hepatitis C. Finally, these limitations in the ‘reach’ of the current model highlight a more significant and fundamental problem which is that the current approach is heavily focused on clinical pathways and outcomes but does not give adequate consideration to the social and structural determinants of health for people with chronic hepatitis C infection and a history of injecting drug use.

AIVL is not alone in having concerns about the current model of care for hepatitis C. *The National Hepatitis C Strategy 2010-2013* acknowledges that the Government’s current model of care document “does not reflect best practice guidelines for clinical care” but also states that despite this it “continues to be used by health professionals and results in outdated service delivery” (DoHA, 2010). To address this situation, the Strategy recommends a review and revision of the current models of care document and also supports the need to develop alternative models of care that utilise GPs, nurses and other primary care providers in the management and treatment of hepatitis C. The review of these guidelines and the models contain therein will be an important step in developing models of hepatitis C management and care that strike the right balance between specialist and mainstream service delivery. AIVL supports the need for a review of the current guidelines and believes it is important that any such revision includes an assessment of how future models will address the specific needs of people with a history of injecting drug use as the group most affected by hepatitis C (NCHECR, 2009a).

AIVL believes that people with hepatitis C require models of access and care that are responsive and take into account the many ways that hepatitis C can affect an individual’s health and wellbeing in the context their broader lives. Current evidence shows that at the end of 2008 there were an estimated 284,000 people who had been exposed to hepatitis C with an estimated 212,000 of those people developing chronic hepatitis C infection (NCHECR, 2009a). Of those people with chronic hepatitis

C infection, at least 80 percent are thought to be people with a history of injecting drug use (NCHECR, 2009a). *The National Hepatitis C Strategy 2010-2013* states as its goal “to reduce the transmission of, and morbidity and mortality caused by hepatitis C and to minimise the personal and social impact of hepatitis C” (DoHA, 2010). With large numbers of people already living with chronic hepatitis C infection and an estimated 10,000 new infections each year (Razali, 2009), it will be a significant challenge over the next three years to achieve the above goals set by the *National Hepatitis C Strategy*.

Despite the size of the challenge, there is no doubt that the current approach to models of access and service delivery for hepatitis C must change. This process of change will need to not only develop, trial and apply new approaches and improve the capacity and outcomes from existing models, but it will also need to occur at a time of unprecedented upheaval within the Australian health system and when the available resources for innovative health care approaches is at an all time low due to the stresses and demands within the existing health system. It is in this context that the need to take a strategic and planned approach to the review and revision of current models of access and care for hepatitis C becomes paramount.

There is general agreement and support within the sector and in the available evidence for the need for change and for better models of access and service delivery for people with a history of injecting drug use (ASHM, 2009). Without careful planning and implementation, there is however a significant risk that the competing political and financial agendas between the Commonwealth and jurisdictions, between the jurisdictions and even within jurisdictions could result in some additional clinical services at the local level but no fundamental change to the way we approach the management, treatment and care of people with chronic hepatitis C infection.

It is important to acknowledge that work to improve the capacity, acceptability and availability of clinical services for the treatment of chronic hepatitis C infection is underway at the Commonwealth and jurisdictional levels. In the past 5-10 years there has been a series of changes at both the policy and service delivery levels aimed at improving treatment access and uptake these include at the Commonwealth level, removing exclusionary criteria from the S100 Guidelines for people with a history of injecting drug use, removing pre-treatment liver biopsy requirement and increasing federal funding for subsidised treatment places.

At the jurisdictional level there has been piloting of GP shared care, setting-specific and multidisciplinary team approaches including expanding the role of

nurses, piloting peer support models and developing approaches that utilise practice nurses, nurse practitioners (NPs) and clinical nurse consultants (CNCs). One jurisdiction (NSW) has also recently commenced a trial of GP S100 Prescribing for hepatitis C treatment. While not all of these initiatives have been evaluated, the available published and interim findings suggest that:

- The removal of the pre-treatment liver biopsy requirement has had an impact on increasing hepatitis C treatment numbers (although this may have reached a plateau) (NCHECR, 2009a);
- Specialist physician/GP based shared care models can be an effective treatment approach for hepatitis C (Spina, 2007);
- Shared care models of hepatitis C treatment can be an effective alternative use of available resources and has the potential to significantly enhance the treatment capacity of the system (Spina, 2007);
- Experienced S100 GP Prescribers may be suitable to initiate as well as manage hepatitis C treatment (see information on current NSW-based pilot later in this paper);
- The use of practice nurses, hepatology nurse practitioners and CNCs can support increased patient access to interdisciplinary coordination and care through appropriate referral and collaboration (Richmond, 2009);
- The availability of appropriately targeted peer support can improve the likelihood of people with a history of injecting drug use accessing, being assessed for and completing hepatitis C treatment (Treloar and Holt, 2008); and
- An appropriately experienced, trained and supported peer support worker can play a unique role in assisting people with a history of injecting drug use to overcome barriers to hepatitis C treatment (Norman, 2008).

While the above initiatives have contributed to increases in the numbers of people accessing hepatitis C treatment, with over 3,500 people receiving treatment for hepatitis C infection in 2007 (NCHECR, 2009a), these numbers are still unacceptably low given the large number of people living with chronic infection. Not surprisingly, there is now an increased focus within government on the need to expand hepatitis C treatment numbers with *The National Hepatitis C Strategy 2010-2013* seeking to double the number of people treated to approximately 6,000 people per year by 2013 in order to have an impact

on the levels of advanced liver disease and those dying from liver disease-related causes (DoHA, 2010). It is in this context of high rates of chronic infection, low rates of treatment access and a strong push to expand treatment uptake that AIVL has identified the need to produce a national discussion paper on developing appropriate models of access and service delivery for hepatitis C treatment and care in our community.

AIVL is the peak national organisation representing the state and territory peer-based drug user organisations and those most affected by hepatitis C in Australia; that is, people who inject or have injected illicit drugs and those on opioid pharmacotherapies. AIVL and its member organisations operate on a peer-based, user-centred philosophy, which means the organisations encourage and support people who use or have used illicit drugs/pharmacotherapy consumers to speak on their own behalf and to participate directly in all levels of the organisations. In this context, AIVL is uniquely positioned to develop a discussion paper on improving not only access to hepatitis C treatment for people with a history of injecting drug use but ensuring comprehensive models of access and service delivery that address hepatitis C in the context of our entire lives.

Terminology – People with a History of Injecting Drug Use:

Throughout this document AIVL has chosen to use the term “people with a history of injecting drug use”. The reason for choosing this term is to acknowledge and encourage further discussion of the complexities and diversity associated with injecting drug use and to ensure that appropriately targeted services and approaches are adopted for those living with chronic hepatitis C infection. As with many issues involving illicit and injecting drug use, there is an absence of conclusive data on the numbers of people with chronic infection who identify as current or active injecting drug users, those in various forms of drug treatment, those seeking to manage their ongoing use, those who have ceased use, etc. AIVL has a good deal of expertise on the subtleties and nuances associated with the way that people identify and are identified in relation to their drug using status. We therefore believe it is important to comment on the interpretation of the available data and what it could mean for models of access and service delivery for people with chronic hepatitis C.

As far as AIVL is aware, the only available estimates of so-called ‘current’ and ‘former’ injecting drug users are based on modelling (NCHECR, 2006) and in this regard should be treated very carefully in terms of the assumptions

and generalisations that can be drawn from them. The problem with applying concepts such as ‘current’ and ‘former’ injecting drug user in the context of models of access and service delivery for hepatitis C is that it does not account for the fact that injecting drug use is often ‘fluid’ rather than ‘absolute’ and people frequently move in and out of periods of active drug use. It is very common for dependent or regular injecting drug users to have a long term involvement in drug use with varying periods of intensive use, infrequent use and abstinence across decades. Indeed, the advent of effective drug treatment, harm reduction approaches and general advances in health care and medicine have increased the life expectancy of active drug users over the past 30 years (Beynon, 2009). This phenomenon however has not been well documented in the literature to date and therefore is not yet influencing thinking and modelling in relation to the numbers of ‘current’ injecting drug users or policy and practice in relation to hepatitis C and ageing. Even if the idea of long term ‘functional’ drug use is too much for some to contemplate, the lack of attention to the issue of illicit drug use and ageing is interesting really given the insistence by ‘addiction scientists’ that dependent drug use is a “chronic relapsing brain disease” (Leshner, 2003).

One of the other problems with taking ‘static’ or ‘point in time’ measures of the numbers of people engaged in active injecting drug use and using these measures for forward projections is that it cannot account for changes in drug use patterns over time. Such changes can result in major fluctuations to the drugs being used, how they are used, who uses them, the equipment used, duration of injecting and the health issues associated with their use. As the key data sources used for the current modelling on the numbers of ‘current’ and ‘former’ injecting drug users in Australia with chronic hepatitis C infection are largely based on research related to heroin injecting before 2005 (NCHECR, 2006), the types of fluctuations outlined above could have a significant impact on the estimates and projections made. These changes or fluctuations in patterns of use also have an impact on the profile of the people who become infected with hepatitis C and the access and care needs of those who go on to develop chronic infection.

It also needs to be recognised that whenever modelling is based (even in part) on research where people were asked to self-identify their drug using status (such as the National Drug Strategy Household Survey) account needs to be taken of the fact that people who inject drugs are understandably very reluctant to admit that they are current or active users due to the stigma, discrimination and punitive responses such admissions often bring. This is further compounded by the fact that people are also concerned about the legal/criminal implications of such admissions. The same issues arise when using research

with people on drug treatment - and pharmacotherapy programs in particular. Making assumptions about the numbers of people who are currently injecting from self-admissions by people in drug treatment will always be problematic due to fears of how such admissions will affect their treatment access, flexibility, self-esteem, etc. This is very important when developing models of access and service delivery for hepatitis C in the context of drug treatment settings such as pharmacotherapy programs. These issues are explored later in the document in relation to barriers to access.

For all of the reasons outlined above, AIVL does not believe it is helpful to invest heavily in concepts of 'current' and 'former' injecting drug users. In AIVL's view, focusing on whether people are 'current' or 'former' injecting drug users is only likely to result in further stigma, discrimination and diminished access to services and care for people with a history of injecting drug use. Rather than forcing people to 'fit' into unrealistic and unhelpful categories AIVL believes the focus should be on ensuring that people who are injecting drugs, people on pharmacotherapies, etc, get access to the types of services and support they need to make decisions, get through treatment, cope after treatment, manage without treatment, etc. The starting point should be integrated, empowering and flexible models of access and service delivery that allow people to identify what they need and how they need across the prevention/care continuum rather than having to deal with confronting and limiting stereotypes.

A peer worker on a pilot project delivering hepatitis C treatment in a pharmacotherapy setting encapsulates some of the fluidity and complexities in the following comment from the project evaluation:

"[One of the] strengths of peer-based services is that there is no us and them, that I identify with the clients which is essentially different to even a very supportive non-peer worker... We've ended up attracting lots of ex-users which makes it more of a minefield, lots of them haven't completed recovery and there are major issues about lapses and relapses. There are all these things about being open, wanting to be abstinent which means they feel that lapses can't be part of the process... A client who makes a bid to stop using and lapses, feels like a failure, they worry that they've let [medical staff] down. All of that makes it very difficult to be honest..." (Norman et al, 2008)

It is often said that once someone has chronic hepatitis C, "it doesn't matter how you got it you just need access to services and care". While there are elements of truth

in this statement, it also needs to be recognised that an approach to hepatitis C care that does not take any account of the practices, rituals and communities that people engage in cannot possibly deliver an integrated, holistic model of care. People with a history of injecting drug use are a diverse group with both common and distinct needs and issues in relation to hepatitis C. Discriminatory attitudes and practices in relation to injecting drug use are entrenched within the health system (NSW ADB, 2001) and in this regard it is assumptions about an individual's drug using status rather than how they identify themselves that often drives poor practice. People with a history of injecting drug use (whether they are currently using or not) can experience barriers to health care and a general questioning of their integrity and ability to know what is best for them.

Having said this however, there is also little doubt that people who are actively injecting and people on pharmacotherapy programs experience more, and more extreme levels of judgement and prejudice than those who have not injected for many years or have never been dependent drug users. Being seen to have "done something to reform oneself and atone for past mistakes" holds considerable moral currency among some health professionals and can effect the way individuals are treated and the quality of care they receive (Parr, 2010).

Current injecting drug use or being on pharmacotherapies is a relevant factor in relation to models of access and service delivery for hepatitis C. Research has shown that current injecting drug users are not treated the same or provided with equivalent access to services as other people with chronic hepatitis C infection such as being given shorter consultations, less access to qualitative testing and diagnosis and less likely to be referred for or receive hepatitis C treatment (Stoove, 2005). While this kind of treatment may not involve overt discrimination, people are aware of being treated differently and drug users often tell each other about such experiences. In this way, the actions of physicians can be very important to the way that people make decisions about whether or not they will engage with services and systems in relation to their health.

Rather than aiming to estimate the numbers of people who are current or former injectors we should focus our efforts on removing barriers to people identifying that they are a person with a history of injecting drug use – whatever that means for their past, present and future. Evidence tells us that almost 90 percent of all hepatitis C infections occur due to unsafe injecting drug use practices (Razali, 2007). This fact alone tell us that we need to greatly improve access to services and care for people with a history of injecting drug use in all their diversity. ■

3 Models of Access and Service Delivery

a. Primary Health Care Models

There is robust literature supporting and advocating the use of primary health care models to improve access to quality services and care but what is less clear is how well primary health care models respond to tackling health inequalities and servicing marginalised groups such as people with a history of injecting drug use. Definitions of primary health care in the literature consistently include principles such as continuums of care (from prevention to management and through to end of life care), health promotion, population health approaches, integrated service delivery, multidisciplinary teams and effective communication between provider and client (including managing health record information systems). There is less research and evaluation relating to how effectively these models of health care have been applied among people with a history of injecting drug use and further, how they can be used for hepatitis C clinical service delivery.

Clinical services for hepatitis C in Australia are provided across a range of different models and approaches which vary from jurisdiction to jurisdiction and are adversely affected across the board by limited resourcing and workforce capacity issues. The primary health care system in Australia is fundamentally based on the general practice model which is largely publicly funded under Medicare but also includes aspects of private funding such as the patient co-payment system, private health insurance, etc. The general practice model is also supported by the wider primary health care sector, including Aboriginal Community Controlled Health Services, state and territory government community health services and a wide range of non-government services. As the need for hepatitis C clinical and social support services grows in Australia, governments are increasingly looking to the primary health care system as a way to provide comprehensive and integrated models of access and service delivery that are person-centred, focused on a continuum of care and can encompass multidisciplinary team approaches to complex and chronic conditions - an approach originally adopted in relation to HIV clinical care (ASHM and NAPWA, 2009). Like HIV however, management and care for hepatitis C involves services engaging with a diverse range

of affected communities some of which experience high levels of social disadvantaged. In this regard, the complexity of the health and social support issues for people with a history of injecting drug use have meant that despite the push to utilise expanded primary health care models for hepatitis C, there is a reluctance among some primary health care providers to take on a wider range of roles for which there is not adequate recognition, resourcing under the current Medicare system or support in relation to managing non-clinical demands. This situation is important in relation to recommendations for piloting and establishing ongoing models of access and clinical service delivery for hepatitis C in the context of the primary health system. The differences in capacity and willingness to incorporate expanded and multidisciplinary team approaches needs to be recognised and it is critical that in addition to resourcing, issues such as workforce capacity and service structure and culture are considered at the planning stages.

In the international literature there is recognition of the need to refocus the health care needs of people with chronic hepatitis C away from an over-emphasis on anti-HCV medications and "curing" infection towards a focus on people's broader health needs (Zevin, 2007). This work suggests the need for treatment and management of hepatitis C to be more broadly defined and that primary health services are the logical source of care for people living with hepatitis C. An aspect of advocating this approach is the acknowledgement that many people with chronic hepatitis C will live full lives with few indicators of the impact of infection highlighting the need for a long term management approach to care (Heller, 2005). There is a further recognition however that moves to reposition hepatitis C management and treatment within a primary health care framework will need adequate resourcing not just to support the delivery of services but to increase the capacity of the workforce to provide comprehensive, integrated and non-judgemental care (Zevin, 2007).

In recognition of the need for effective responses to the serious health issues faced by injecting drug users including hepatitis C when they have poor access to appropriate health services, in 1999 the Victorian Government provided funding for five IDU primary health

care services. This funding was aimed at establishing and trialling in Victoria the concept of primary health services, combining both a fixed site and a mobile outreach service to meet the primary health needs of street-based injecting drug users who were at high risk of BBVs, overdose and other drug-related harm (McDonald, 2002). Some of these services included Innerspace (formerly Next Door), the Living Room and Healthworks. Other jurisdictions have also supported the concept of IDU primary health care services for many years through the Kirketon Road Centre (KRC) in NSW and the SCIVAA PHC Centre in Queensland. All of these services were established with the aim of providing an integrated and holistic approach to addressing the primary health care needs of injecting drug users.

This involved developing a service structure and culture that was welcoming for highly marginalised IDU many of whom experienced periods of homelessness and ensuring the service was staffed by people with a good level of knowledge and understanding of the broad range of issues for injecting drug users; not simply understanding their clinical needs. It also meant having an ongoing commitment to ensuring the attitudes and values of staff and the general culture of the service did not create barriers to service access. At the structural level changes were required to the: physical environment and layout of the service; removing the need for a Medicare card to access care; bringing a range of clinical and allied health services to the central primary health facility rather than persisting with an ineffective referral system; etc. For some services it has also involved operating mobile health services to take the health care to the clients rather than expecting clients who may be homeless, supporting a drug dependency, living in poverty and managing multiple health, legal and social problems to come to them.

Despite the fact that injecting drug users have very poor standards of general health and low levels of access to primary health care services that are well documented (Reid, 2000), the types of IDU-focused primary health care services outlined above continue to be few in number. Even if such tailored services were to be made more available however, not all people with a history of injecting drug use who are living with chronic hepatitis C infection will want to access primary health care delivered in this way. As noted in the literature, the majority of these services were developed and designed to address the health needs of largely homeless IDU in areas of street-based injecting scenes (McDonald, 2002).

People with a history of injecting drug use who are living with chronic hepatitis C infection are heterogeneous group and subsequently have a diverse range of health

care needs that will require a multi-faceted approach to the delivery of health care services. Such an approach will require the further development of targeted IDU primary health care services along the lines of existing models as well expanding the role that services such as Aboriginal Medical Services are undertaking in relation to Indigenous IDU health. In addition to these 'targeted' primary health services, it will also require an honest examination of the substantive general practice-based model and how it can be supported to take a stronger role in providing integrated primary health care for a significant number of people who have a history of injecting drug use and chronic hepatitis C.

One of the key issues of consideration in seeking to expand access to primary health care among people with a history of injecting drug use is the fact that a growing number of people on opioid pharmacotherapies are already being prescribed through general practice (AIHW, 2009). With high levels of chronic hepatitis C infection among people on opioid pharmacotherapies (Day and Haber, 2009) there is the potential to further develop GP shared care models, the use of CNCs and practice nurses and to consider the wider application of S100 GP prescribing for hepatitis C treatment. These new models of access and service delivery for hepatitis C will however test the system's capacity to develop truly responsive, integrated, person-centred approaches that are suitable for the specific needs of people with chronic hepatitis C infection.

While the barriers to access and service delivery in relation to hepatitis C are considered in detail in the next section of this paper, it is important to recognise that it will not be sufficient to simply 'overlay' access to hepatitis C treatment on top of current approaches to pharmacotherapy prescribing in general practice. It is essential to acknowledge that the structure and approach of the opioid pharmacotherapy program creates very real barriers to open and honest communication between the GP prescriber and the client. AIVL believes there is a need to pilot innovative strategies for improving the communication between the GP prescriber and pharmacotherapy client prior to the addition of another complex form of treatment. The use of practice nurses can be very effective at increasing the capacity of the health service to provide a more comprehensive service in relation to hepatitis C but will not on its own remove the structural and policy barriers to communication.

This is not to suggest that all GPs or practice nurses have poor relationships with their clients – they do not. Rather, it is the barriers created by the illicit nature of drug use and the underlying punitive approach of the opioid pharmacotherapy program that form barriers

that will prevent communication on some important medical issues, even if, broadly speaking, the provider/client relationship is good. Research shows that people with a history of drug use are very reluctant to speak with health care workers about their drug use for fear of poor treatment and discrimination (Aitkin, 2002). A well trained and supported peer worker can negate those fears and support indepth discussions which would be very unlikely to occur in a more formal clinical setting. Peer workers are also a very effective option in resource poor settings such as general practice where it is very unlikely that a busy practice nurse would have the time available to have such discussions even if rapport could be established.

A pilot project designed to evaluate the impact of employing peer workers as part of a multidisciplinary primary health care approach to providing hepatitis C clinical services in pharmacotherapy settings found very positive outcomes in the area of improved health care relationships. In particular the project found that if the peer worker is included as a full member of a multidisciplinary clinical team, they can act as a 'bridge' and 'translator' between a range of health professionals and the client. This can allow for the development of a full clinical and psychosocial picture and support better health outcomes for the client. The extent to which pharmacotherapy clients contemplating or engaging in hepatitis C treatment through the pilot project saw the role of the peer worker as helping clients and doctors communicate is highlighted by the following client comments:

Client A: "Well the doctors are in touch basically by having the peer worker there. She or he can tell the doctor exactly what the patients are feeling and get through to them."

Client B: "Yeah. And for some people it might be easier to talk to someone like [the peer support worker] rather than the doctors so you still get the information across."

Client C: "And some people feel threatened by the doctors and they can talk to [the peer support worker] and let the doctors know how they feel." (Norman et al, 2008)

While it is acknowledged that the above project was undertaken in a multidisciplinary community-based AOD service rather than the general practice setting, we still believe there are some key learnings that can be taken from this project for general practice particularly in relation to GP Shared Care models. The delivery of

integrated primary health care models through general practice particularly for complex and chronic conditions is set to become a major feature of the Australian health system. Although the current health system reforms are discussed later in this section, it is important to note that the health reform outcomes are unlikely to be met if ways to make general practice more accessible to people with a history of injecting drug use are not part of the process. Bringing the domains of hepatitis C, injecting drug use and primary health care together to create quality models of access and service delivery for those most affected by hepatitis C will need to acknowledge the complexity of health issues and the barriers to addressing them regardless of where the care is delivered.

The relationship between the primary health care system and the management of complex and chronic diseases such as hepatitis C among people with a history of injecting drug use is articulated in the following comment:

"Injecting drug users have primary healthcare needs that deserve attention. Research has shown that drug users are not receiving services commensurate to their needs, particularly mental health, medical care, financial and employment counselling. The inability of the primary health care system to provide effective services for people who inject contributes to debilitating and irreversible health problems." (Anex, 2004)

b. Chronic Diseases Management Models

"Chronic diseases tend to be complex conditions in how they are caused, are often long-lasting and persistent in their effects and can produce a range of complications." (AIHW 2002)

AIVL believes chronic hepatitis C infection should be acknowledged as a complex and chronic condition and perhaps more importantly in relation to models of access and clinical service delivery, needs to be approached through the lense of a chronic disease management framework. The World Health Organisation defines a chronic disease as "diseases of long duration and generally slow progression" and chronic conditions as "health problems that persist across time and require some degree of health care management" (WHO, 2002). While there is not a single agreed and comprehensive definition of what constitutes a 'chronic condition' in

Australia, AIVL believes the broad definition applied by the WHO does encompass the experience of chronic hepatitis C infection for many people living with condition and associated comorbidities. The *National Hepatitis C Strategy 2010-2013* also confirms that hepatitis C is a chronic disease for the majority of people:

“People with hepatitis C are at risk of progressive liver disease. Lifestyle risk factors that make people more likely to develop progressive liver disease include heavy alcohol intake and fatty liver disease (associated with obesity). However, hepatitis C is significantly different to other chronic diseases as a cure is possible for many people, possibly 50-80% of those treated. But while the number of people on treatment remains as low as it is, hepatitis C remains a chronic disease for the majority.” (DoHA 2010)

While communicable diseases such as hepatitis C have not been included in all definitions of chronic disease - and indeed have been specifically excluded in some policy frameworks - AIVL would argue that the mode of disease onset (communicable or non-communicable) should not be used in an exclusionary manner for the purposes of defining chronic conditions. Some work on classifying chronic conditions in the Australian context has recognised “persistent, communicable diseases” in addition to non-communicable chronic disease (ASHM and NAPWA, 2009). Such “persistent communicable diseases” could include conditions such as HIV, chronic hepatitis B and chronic hepatitis C. This would be consistent with the National Public Health Partnership Strategic Framework on Preventing Chronic Disease 2001 which took a ‘clustering’ approach to how it defined the range of health priorities and associated conditions that constituted “chronic diseases” under the framework. It should be noted that the NPHP Framework only referred to non-communicable chronic diseases, however it is the principles that are applied rather than the diseases identified within the document that are of value for chronic hepatitis C.

The framework acknowledged that although there were significant disparities in the rates of the various priority conditions in different population groups, the diseases or conditions also had a range of important common characteristics that made it strategic to address them under a chronic diseases management framework. These common characteristics were:

- The diseases shared common risk factors;
- A large proportion of the disease burden could be prevented through changes in lifestyle and early detection of health problems; and

- Effective preventative action on a national basis had the potential to make a significant contribution to improving health outcomes and health related quality of life, reducing inequalities in health, and minimising unnecessary demand for health care services (NPHP, 2001).

AIVL would argue that the common characteristics that form the basis of the rationale for ‘clustering’ certain chronic disease priorities under the NPHP Strategic Framework can equally apply to the ‘clustering’ of persistent communicable diseases such as chronic hepatitis C, chronic hepatitis B and HIV. Furthermore, the spectre of hepatitis C as a preventable chronic disease that significantly affects people who are socially and economically marginalised and is not only one of the most common notifiable diseases in the country, but also the leading cause of liver transplantation in Australia, all add to the case for hepatitis C to be treated as both a complex and chronic condition.

The fact that there is an effective treatment available for chronic hepatitis C infection that has been termed “a cure” has led some to question whether hepatitis C should be considered a chronic condition. AIVL would argue that very poor levels of treatment access and uptake, the fact that between 20-50 percent of people will not have a successful treatment outcome, that there can be significant and prolonged post treatment side-effects and that even a successful treatment outcome does not necessarily reverse liver damage and associated health problems calls into question the extent to which ‘curability’ should be considered.

That a significant number of the people with chronic hepatitis C infection and a history of injecting drug use are ageing and that many are already living with multiple health and social issues associated with long term drug dependence, are further reasons why hepatitis C should be approached through a chronic disease management approach. Australia has a National Chronic Diseases Strategy (NCDS) which focuses on the need to adopt enhanced primary care approaches in the management of chronic diseases including the integration and continuity of prevention and care, self-management strategies, multidisciplinary team approaches and evidence-based health services (NPHP, 2001). While the NCDS does not identify hepatitis C as a chronic condition, the principles underpinning the service improvement frameworks for the chronic diseases identified have direct relevance for managing hepatitis C in the community.

This is supported by the fact that Hepatitis C Victoria recently were recently successful in gaining the first hepatitis C specific funding from Commonwealth Department of Health and Ageing – Chronic Disease Self Management and Lifestyle Risk Modification Grant

Program to fund a project which provides chronic disease management information to people living with hepatitis C. This is a positive sign which further endorses the fact that hepatitis C must be accepted under current policy frameworks as a complex and chronic condition if we are to develop effective responses.

In AIVL's view, it is a good sign that the NCDS and other relevant policy frameworks such as the National Primary Health Care Strategy (NPHCS) are recommending much needed reform to the way that complex and chronic health issues including hepatitis C are managed within the Australian health care system. The NCDS and the NPHCS have both recognised that chronic diseases are an increasing problem in the Australian community and one which is set to worsen in an ageing population. In this regard, these strategies have identified the subsequent need to move away from a health care system dominated by the acute care model to one that is responsive to both preventing and caring for long term illness across a person's life course. Successful reform to a chronic disease management framework for hepatitis C will therefore involve enhanced models of primary care that include multidisciplinary team approaches which address both clinical and non-clinical service needs including peer support.

c. Peer Support Models

Peer support can play a crucial role for those isolated from their families, the health and social welfare system and the rest of society due to the stigma associated with illicit drug use. For many people with a history of injecting drug use, the stigma attached to injecting translates into people feeling unwelcome in health services, including drug treatment services, and being distrustful of their motives and cynical about the information and services provided. After many years of contact with the health system, people with a history of injecting drug use often express reluctance and fear about disclosing current or past injecting drug use and/or discussing injecting related health issues due to the likelihood of discrimination (Aitkin, 2002). This reluctance often results in a breakdown in communication and trust between the clients and service providers. It is common for people on pharmacotherapy programs to express a desire to have 'as little contact as possible' with the service in order to protect themselves (and their children if they have them) from undue scrutiny, from punitive responses and to preserve any 'privileges' that they may have been able to secure such as take away doses (AIVL, 2008).

In the context of models of access and service delivery for hepatitis C among people with a history of injecting drug use, peer based approaches can provide a way to access

'hidden populations', convey information and encourage learning among people who may be indifferent or unreceptive to other models. Peer-based approaches also address what are considered 'high-risk' practices with a level of understanding and pragmatism that considers the person's entire life circumstances as well as an individual's capacity to make changes in their behaviour or indeed in their life at that time. One of the most valued characteristics of peer support workers in the literature is the sense that peer workers have a greater ability to fully appreciate the problems people are experiencing and therefore avoid making impractical suggestions about possible solutions (Aitkin, 2002). Peer workers can also assist in establishing more effective communication between clients and service providers and act as a 'bridge' in building or rebuilding trust and credibility.

The *National Hepatitis C Strategy 2010-2013* has also identified the need for integrated IDU peer support in hepatitis C service delivery citing the growing evidence base in support of the effectiveness of such approaches. The Strategy highlights that the evaluation of such programs have shown a strong preference among current IDU and people on pharmacotherapies for support provided by other people who inject drugs who have hepatitis C. It recommends as an area of priority action the need to increase the participation of peer support workers across the health workforce in the delivery of hepatitis C management and the integration of specific peer support approaches for people who inject drugs (DoHA, 2010).

Principles that Underpin Peer Support:

A strong argument for the use of peer-based approaches lies in the nature of "peerdom", the importance of identity and identification among marginalised populations and the credibility that is generally accorded to peer-to-peer interactions (Norman, 2008 and Aitkin, 2002). As noted above, peer workers can bring a 'person-based', 'experience-based' and 'message-based' credibility to health promotion in the context of intimate, illegal and stigmatised behaviours. The AIVL Peer Education Framework notes:

"Peers are more likely to believe and trust information and ideas that come from someone with credibility as a user within their network or group; they are more likely to listen to someone they respect and know has personal experience of 'living the life' (e.g. scoring, injecting, hanging out, being on pharmacotherapies, having hep C, dealing with services and discrimination), of negotiating 'modes of desire' of feeling the pleasure that comes with using illicit drugs and

constructing and negotiating risk. Without that experience, a peer worker's knowledge of his/her portfolio would be sorely lacking" (AIVL 2006).

Peer-based approaches also have a strong role to play in assisting people to make difficult decisions about diagnosis, treatment and clinical services. Properly trained and supported peer workers who are fully integrated members of an multidisciplinary primary health care approach have the ability to translate complicated information and medical jargon into manageable pieces of information to support informed decision making. In making decisions about treatment options, care coordination and self-management strategies, people can often feel overwhelmed by the level and type of information being provided by health professionals and peer support workers can help make sense of this process.

Peer support workers can also help the person to relate the information to the broader context of their lives. This is particularly important in the area of hepatitis C management and treatment for those on opioid pharmacotherapies either in specialist clinics or through community-based prescribing in general practice. It is critical that people have the space and time to openly and honestly discuss issues such as current drug use, their living arrangements, support needs, etc, with someone they trust and someone who does not have direct control over their pharmacotherapy. In short, people will choose to avoid the whole issue of hepatitis C testing, diagnosis, treatment and management if they are concerned it may negatively impact on their pharmacotherapy arrangements. This is highlighted by the following quote from a peer support worker on a project focused on hepatitis C treatment in pharmacotherapy settings:

"Whether the judging is real or perceived, it's still very real to clients and it's a huge divide to engage across. Having a peer worker in the role means that I know this territory because it's my reality too. A lot of what I talk to clients about is drug use. I'm very pragmatic, shit happens, people lapse. Lots of clients on treatment have profound fears that drug use will impact on treatment and they can't talk to clinicians about this, I clarify that this isn't going to undermine the treatment, it's about being stable." (Norman, 2008)

AIVL believes it is very important to be clear and unambiguous about the types of approaches which constitute genuine peer support for people with a history of injecting drug use. From AIVL's perspective, the boundaries around peer education and support

are becoming increasingly blurred whereby in some contexts almost any form targeted information provision to illicit drug users is labelled as "peer education" or "peer support" regardless of the extent to which peers are involved in the process. Some of the key considerations are the degree of ownership by the peers themselves and their level of involvement and participation in the process. As a general rule, if the 'peer education' or 'peer support' process is largely defined and restricted by the needs and protocols of the service or organisation rather than by the issues and needs of the peer group, then it is not a peer-based approach regardless of whether there is peer involvement at the level of workers, volunteers, etc.

In contrast, genuine peer-based approaches are designed, developed, implemented and controlled by peers. While it is beyond the scope of this paper to explore the complex issue of 'who is a peer', this issue has been explored in some depth in the AIVL National Peer Education Framework. Further information on some of the key principles that underpin IDU peer-based approaches are also provided at Appendix 1 of this document. There is also strong evidence to support the fact that many people with a history of injecting drug use (particularly current IDU and pharmacotherapy consumers) do not view people without direct personal experience of injecting drug use as their peers for the purposes of hepatitis C peer support (Aitkin, 2002 and Norman, 2008).

Rather than viewing the above preference for IDU peer support as a criticism of other health professionals, AIVL believes it is important to understand this preference and view it as a way to strengthen existing services and to significantly increase access to information and support for a highly marginalised group in the community. The evidence demonstrates that the addition of genuine IDU peer support can be a valuable clinical tool and greatly enhance the likelihood of people with a history of injecting drug use presenting at health care services. AIVL believes that the inclusion of IDU peer support should be considered an essential component of delivering enhanced primary care services for hepatitis C.

Evidence of the Effectiveness & Benefits of Hepatitis C IDU Peer Support:

AIVL and its member organisations play a crucial role for people with a history of injecting drug use who are socially excluded and marginalised due to the stigma and discrimination associated with illicit drug use. As a peer-based organisations run by and for people who use/ have used illicit drugs, the AIVL network is in the unique position of being able to both represent and address the issues and needs of people with a history of injecting

drug use. Through our direct experience the AIVL network provides governments, services and the broader community with the 'drug user perspective' on a range of issues in relation to illicit drug use including hepatitis C. Equally, as 'peers' we also have the credibility and trust required to reach people with a history of injecting drug use and provide meaningful support.

Australian peer-based drug user organisations have significant experience in the provision of intentional peer support initiatives including peer support groups, individual counselling and support and advocacy and representation. The majority of AIVL member organisations operate well-established peer support programs covering an extensive range of issues and needs for people with a history of injecting drug use including advocacy, support and referral on drug treatment, hepatitis C, drug related health issues, HIV, legal issues, housing, parenting, welfare issues, employment, discrimination, etc.

In relation to hepatitis C peer support for people with a history of injecting drug use, research has shown that providing such peer support can facilitate entry into hepatitis C treatment. "In particular, peer-support programs in Australia and the US have demonstrated their value in assisting clients to access, be assessed for and complete hepatitis C treatment" (Treloar and Holt, 2008). In addition to the activities and programs provided through peer-based drug user organisations, over the past 8-10 years there has also been a number of research, partnership and pilot projects that have specifically focused on hepatitis C peer support for people with a history of injecting drug use. All of these projects have involved partnerships with peer-based drug user organisations and include effectiveness evaluations.

In 1999/2000 researchers from the Burnet Institute partnered with a needle and syringe program (NSP) in Melbourne's inner west and VIVAIDS to investigate the effect of utilising peers to conduct hepatitis C testing, counselling and education among the IDU clients of the NSP. Over 300 counselling episodes were provided, and 47 IDUs who were not tested in the previous 12 months agreed to be tested and given full pre and post test counselling. People were also interviewed about the reasons why they hadn't tested and their levels of knowledge of hepatitis C and related risk factors. Amongst clients at this busy NSP, the researchers found that "many displayed a frightening lack of knowledge and confusion about hepatitis C". In addition "nearly 45 percent claimed to have received no pre- and post-test counselling when tested by their methadone prescriber or GP, and some claimed medical practitioners had given them inaccurate information about hepatitis C." Following

peer-delivered testing and counselling, the researchers found that the incidence of safer injecting practices increased significantly, with clean equipment being used more often (84.2% vs 60%) and hand washing prior to injecting also increasing (43.4% vs 27.5%) (Aitkin, 2002).

The project also identified some very important factors in relation to barriers to service delivery and to hepatitis C management in particular. A majority of the clients interviewed stated they had a regular doctor but a number of them said that they had felt unable to ask for hepatitis C testing from that clinician because of a fear of disclosure of drug use and the likelihood that discrimination would follow. The main reasons respondents stated for agreeing to hepatitis C testing and counselling through the project, related to the convenience, ease and comfort of being tested by a peer in a familiar environment and due to a reluctance to disclose their IDU status to their doctor and/or their expectation of poor treatment in other clinical settings. In the counselling sessions people were largely seeking practical, jargon-free information on both understanding test results but also more personalised information on prognosis and managing hepatitis C infection. People described not being believed by healthcare workers when seeking help and being aware of judgmental attitudes. The researchers concluded that "testing and counselling improve IDUs' ability to avoid harm, and that delivery of these services by a trained and experienced peer is an appropriate and effective model" (Aitkin, 2002).

In the area of hepatitis C treatment in pharmacotherapy settings one of the best examples of an effective peer support model is the Healthy Liver Clinic (HLC) project conducted through a partnership between VIVAIDS – Victorian Drug Users Group (now Harm Reduction Victoria) and Turning Point Alcohol & Drug Centre. The HLC project was independently evaluated with the main findings and conclusions published. The aim of the evaluation was to examine both service user and peer worker perspectives regarding the integrated substance use/HCV treatment service model, with a particular emphasis on the role of the peer worker in the service model. In addition, the evaluation aimed to provide addiction and HCV specialists with information to facilitate improved health care relationships when treating patients with substance use problems for HCV (Norman, 2008).

The HLC was designed to provide treatment for chronic hepatitis C infection in a drug treatment setting, providing peer support for people with a history of injecting drug use. The peer worker was in large part intended to provide a link between patients and clinicians, and to support patients in a manner that only a peer can do. The peer worker explained that her role

was “helping people to overcome practical barriers [to hepatitis C treatment] such as transport and housing problems, trying to meet their [the clients’] social and emotional needs and helping them to deal with the side effects of treatment” and to “act as an advocate and translator for clients in their dealings with clinicians” (Norman, 2008).

Some key findings in the report on the pilot HLC model with regard to the role of the peer support worker were:

- Most clients said they would not have started treatment without the HLC;
- Clients spoke about having confidence in the treatment and treatment team and feeling at ease and comfortable at the HLC;
- Clients felt there was no stigma attached to attending the HLC and considered staff to be non-judgmental, knowledgeable, friendly and dependable;
- The broad supportive role which clients described for the peer worker may reflect the complex needs of substance using clients;
- Having this role helped clients and doctors communicate;
- Nothing needed to be hidden from a peer;
- The peer worker identified the importance of being employed and linked to a drug user organisation with experience in peer worker models, highlighting the support she received through such an arrangement (Norman, 2008).

Clients of the HLC were interviewed for the project evaluation. Many of the comments made were very supportive of the peer worker’s role. They included the following:

“...my needs are met in a whole lot of different ways, from personal to support, to my addiction, to ramifications from the addiction”;

“...I think she [the peer support worker] has made the difference between sticking to this or not”;

“...if we didn’t have the peer support worker this program wouldn’t be running”;

“...the doctors are in touch basically by having the peer worker there. She or he can tell the doctor exactly what the patients are feeling and get through to them [the doctors]” (Norman, 2008).

One of the key aspects of the HLC pilot model was the fact that the peer worker was considered part of the clinical team and was therefore available ‘on-site’. The model was described as a peer-based integrated model of hepatitis C care at a multidisciplinary community-based drug and alcohol service. The HLC team consisted of sessional medical practitioners, a visiting specialist physician, peer worker, nurse and pharmacist and access to other on-site allied health professionals as required. In addition to the individualised support provided by the peer worker, the HLC staff also facilitated a weekly after-hours support group. The peer worker was employed by the local drug user organisation which provided much needed supervision and support for the worker. The main roles the peer worker played within the HLC team was to facilitate referrals and recruitment to the service, provide support to the people considering and undergoing treatment and enhance patient adherence and support within the service (Norman, 2008).

The fact that the HLC peer worker operated as part of a multidisciplinary team is an important and unique aspect of the model in that almost always, peer workers are not viewed as having anything to offer in the clinical setting and if peer support workers are available at all, they are usually based away from the liver clinic or other hepatitis C clinical setting. Health care providers generally view peer support as an ‘external’ or ‘allied’ health service provided by an NGO and accessed only through referral. This referral based approach to peer support relies on the person receiving hepatitis C care to seek out such support including covering the additional time and transport costs associated with getting to other services. The aim of the HLC model was to mirror the client’s needs rather than forcing clients to fit into an existing service or treatment model.

The evaluation of the HLC highlights that there should not be an assumption that clients attending a specialist liver clinic are doing so because they intend to commence hepatitis C treatment. Instead the report points to the fact that people may simply be wishing to evaluate their condition and begin the process of engaging with clinicians on their hepatitis C (Norman, 2008). This is a particularly important point for people with a history of injecting drug use who may have had very limited opportunities to speak to health professionals about their hepatitis C in the past and may not be ready to enter treatment. There is generally quite a poor level of understanding among health professionals and policy makers of the reasons why hepatitis C treatment uptake is so low among people with a history of injecting drug use. International and now Australian research is however increasingly highlighting the need for more inclusive, supportive and comprehensive approaches to hepatitis C care (Sylvestre, 2004).

Hepatitis C requires an ongoing management approach and it can take many years for people to reach a decision about commencing treatment or indeed exploring options for self-management and care without treatment. For this reason, it is critical that hepatitis C management including integrated peer support is provided in both specialist and primary care settings so that people can engage over time and in a way that best suits their needs. Developing integrated, client-centred and multidisciplinary models of hepatitis C service delivery is consistent with enhanced primary care and chronic disease management approaches and should be the basis of increasing access to hepatitis C service delivery for people with a history of injecting drug use.

Despite the quality outcomes from the pilot project, unfortunately the model adopted in the HLC project has not been used as the basis for ongoing service delivery in Victoria. The good news however is that the principles of the HLC model have been adopted in another pilot project in NSW. The ETHOS (Enhanced Treatment for Hepatitis C in Opioid Substitution Settings) Project is currently underway in a number of health services across NSW. AIVL has participated in the National ETHOS Steering Committee, NUAA (NSW Users & AIDS Association) on the NSW ETHOS Pilot Projects Committee and Harm Reduction Victoria have provided ongoing advice to the project. This project is being conducted by the National Centre in HIV Epidemiology and Clinical Research (NCHECR) with funding through the Commonwealth Department of Health & Ageing and NSW Health to 2010. The aim of the ETHOS Project is to:

“research and pilot models of service delivery to enhance HCV treatment assessment, uptake, and outcomes among people on drug dependency treatment” (NCHECR, 2008)

Drawing on the findings of the HLC Project, ETHOS is piloting a number of hepatitis C peer education and support activities as part of an integrated service delivery model. The importance of including peer support in all of the pilots from the outset of the project was raised by both AIVL and NUAA in our roles on the project steering committees. Despite this advice, the peer support activities have been added to project models after the commencement of the ETHOS Study rather than designed as an integrated whole in the case of the HLC pilot. Nevertheless, following an AIVL presentation to a training workshop for the service providers participating in the ETHOS Project, AIVL (along with NUAA and Harm Reduction Victoria) were asked to develop a national discussion paper identifying the need for and efficacy of hepatitis C IDU peer support and a national training approach to support the inclusion of such peer support in the ETHOS Project.

The discussion paper was subsequently considered by the ETHOS Steering Committee and as an outcome of this process and independent discussions between NUAA, NCHECR and one of the opioid pharmacotherapy services involved in the pilot, this project site has agreed to incorporate a peer support component into their service model. The peer support component is along the lines of the HLC approach including the employment of a part time peer support worker for a 3 year period who is based on-site but employed and supported through the state drug user organisation – NUAA. The project is based in the Hunter/New England Area Health Service. Since the employment of the peer support worker, the service has tripled the number of people on hepatitis C treatment with six people enrolled in treatment (two of those have completed and four continue) as at September 2010. It has also made a significant difference to the level of general engagement with clients on the issue of hepatitis C and hepatitis C treatment.

As with the HLC pilot, the ETHOS Hunter peer support worker has gained a great deal of trust among the clients as they view the peer worker as someone they can rely on to protect their rights, their interests and very importantly, their confidentiality. This is essential for clients of opioid pharmacotherapy clinics as too often they have had poor experiences at the hands of the health system and are very reluctant to trust clinical staff. This can create complex issues for peer workers as they negotiate both their professional relationships with other clinic staff and their peer-based relationships with the clients of the service. It is this process of managing relationships, expectations and boundaries that can be particularly difficult for peer workers and makes it essential that they are provided with adequate training, supervision and support. The HLC pilot also identified these issues along with the value of having the peer worker employed and supervised by the statewide peer-based drug user organisation while also being an integral member of the clinical multidisciplinary team. These issues have been equally present in the ETHOS Hunter project.

Identifying the right individuals to employ as hepatitis C peer support workers in clinical settings has been a major theme in both the ETHOS and HLC projects. There is a growing consensus within the AIVL network that, just like other professional peer-based roles, hepatitis C peer support workers require a range of essential characteristics. In short, it is not enough to simply ‘be a peer’ in order to be an effective peer support worker under this type of model. This is explained by the following comment from the ETHOS peer worker:

“... as a peer support worker you really do need education [and formal training]. I am a trained welfare worker and have a diploma in community services up my sleeve and I need all these skills to be able to work with doctors and nurses and also the peers as there is a lot of things you need to know and hepatitis C is a very hard disease to understand if you haven’t studied it. People in general will ask you very complicated things about bloods and treatment options so I think that you could be thrown into a position where you could drown if you had no background in the area.”(Hope Everingham, NUAA Newcastle Hepatitis C Peer Support Worker).

The ETHOS Hunter Project has also highlighted the importance of regular supervision and debriefing both through NUAA as the main employer but also with the Nurse Unit Manager and the hepatology nurse if the peer support worker is going to function as an effective and equal member of the project team. As the ETHOS Hunter Project is also part of the broader research study as outlined above, the peer worker has also identified the importance of the relationship with the research and funding body for the project which is NCHECR. All of these relationships are central to the success of the project and to why the existence of a fully integrated and supported peer worker can make the hepatitis C treatment experience so much better for clients.

As was found in the HLC pilot, there has been a tangible and very positive impact associated with the inclusion of the NUAA hepatitis C peer support worker in the ETHOS Hunter Project. There is a feeling that staff within the pharmacotherapy clinic are now more aware and interested in the peer or consumer perspective and the value a peer worker can add if they are fully integrated into the service model. The NUAA peer worker has worked with the clinic to identify those team meetings where it may not be necessary or appropriate for the peer worker to attend particularly in relation to pharmacotherapy case management meetings for each client. Having said this however, setting such boundaries can be quite complex particularly if there are issues that clients have only disclosed to the peer worker or where the peer worker may be able to provide an alternative perspective on issues that may impact on their hepatitis C as well as their pharmacotherapy treatment. The way that pharmacotherapy is delivered and how such treatment decisions can act as barriers to hepatitis C treatment access is discussed more later in the paper.

In addition to the integrated peer support approach being utilised in the Hunter, NUAA is also piloting a model of hepatitis C and liver health peer support at a private clinic¹ in Sydney South West Area Health Service (SSWAHS). This particular clinic had experienced some difficulties in the past with relations between consumers and staff and also between clients. The clinic was already an ETHOS participant, with an outreach nurse from the local primary liver clinic present one day a week. The liver clinic is housed with the local public hospital and is located a number of suburbs away from the clinic site. The model in SSWAHS differs in a number of important ways from the Hunter model including:

- There are two peer support workers, rather than one;
- These peer support workers are clients of the clinic itself;
- The peer support workers are only at the clinic for 4.5 hours per week, rather than the 2 days per week spent at the clinic by the Hunter worker;
- As mentioned above, the hospital and liver clinic, along with allied health specialists such as psychologists and nutritionists are located some distance away while the Hunter site is on the hospital grounds and much closer to allied health services;
- The peer support workers are able to support one another as well as being able to attend debriefing and ongoing training sessions at NUAA due to being based in Sydney; and
- The peer support workers are integrated into the clinic waiting room.

It remains to be seen, through the external evaluation to be undertaken in 2011, just what impact these differences will have on the outcomes of the project. It is certainly the case that staff and clients of the clinic noticed an almost instantaneous change in the “atmosphere” of the clinic on the days the peer support workers are present. Given the often fraught nature of the atmosphere previously, this in itself is contributing to people being willing to stay and talk to the peer support workers about liver health and so on, and is in this sense successful.

On the other hand the physical distance from the hospital and its services means that supporting a person to go to an appointment with a psychologist or to attend the liver clinic is more time-consuming and more difficult for both the peer workers and the clients to commit to and manage. Nevertheless, the outreach nurse and the clinic

staff are very supportive and the peer workers have the close support of NUAA, including a dedicated NUAA staff member who is developing training and debriefing tools. Although the evaluation will identify the full effect of the differences in the peer support models in a few months, the pharmacotherapy service involved in the project has already identified a range of benefits directly associated with having the peer workers within the clinic in written feedback to NUAA.

In particular the service highlighted the ability of the peer educators to engage “hard to reach clients”, using local knowledge and familiarity within the clinic including engaging with CALD clients and their peer networks. The service has stated this has been reflected in the increased numbers of clients coming forward for HCV testing and assessment for treatment. The service has also identified that the number of clients being seen by the HCV Clinical Nurse Consultant (CNC) for brief interventions has decreased as these are now seen by the peer workers and this has greatly increased the interventions for testing, assessment and education that are now occurring. There has also been an increase in referrals to the specialist physician for consideration of treatment.

The service has also attributed a range of more general positive developments within the clinic to the work and presence of the NUAA peer educators. The peer project has been instrumental in introducing initiatives such as healthy snacks provided each week which have been appreciated by the client group and have proved to be an effective way of highlighting the weekly HCV clinic. The peers have also assisted in the organisation of other projects for Hepatitis Awareness Week and other hepatitis related outreach education activities. Clients too are now recognising the knowledge and assistance of the peer educators and this has led to clients seeking out the peers for advice and information on accessing testing and treatment outside of the set HCV Clinic times.

The service has acknowledged the strength of the working relationships between the clinic staff and the peer workers and has admitted the outcomes from the project have exceeded expectations. The success of the project thus far has led to the service approaching NUAA to consider additional future roles for the peer workers including training in providing pre and post-test discussion, phlebotomy to allow them to offer testing outside of the set HCV Clinic times and assisting with enrolling clients in the ETHOS research cohort. There has also been interest from at least four other clinics and health services in incorporating the NUAA peer education and support approach into their programs and services. The main issue for NUAA in responding to this growing

interest in the use of peers to address barriers to access and service delivery for hepatitis C in pharmacotherapy and other health settings is access to adequate resourcing. Without appropriate resourcing for both the peer workers themselves and for NUAA to allow them to identify, train, support and coordinate the peer workers, the benefits of peer support in this context cannot be realised or sustained.

Supporting IDU Peer Workers:

The final issue that needs to be discussed in relation to developing models of hepatitis C peer support for people with a history of injecting drug use is the importance of including adequate training and ongoing clinical supervision and support for peer workers. This is particularly important for peer workers who have hepatitis C and a history of injecting drug use. The HLC Project identified the significance of this issue and outlined in the evaluation report a range of specific issues and experiences that need further examination in the context of continued investment in and support for hepatitis C IDU peer support. Some of these issues included:

- Ensuring adequate training and ongoing professional education opportunities for the peer worker(s) so they can provide accurate and up-to-date information for clients;
- Employing peer workers is not just about “getting any peer” and the participants in the HLC project identified the individual characteristics and personality of the peer worker as key;
- The fact that the peer worker was a ‘peer’ was important in the additional skills, understanding and experience that clients saw the peer worker as bringing to the multidisciplinary team;
- But this ‘peeriness’ also highlighted a complex issue about confidentiality for the peer worker and questions about the extent to which peer workers should have to divulge their own drug use to both clients and other team members;
- The peer worker raised the fact that she sometimes felt distrust from other health care workers highlighting the critical role of training for the staff of multidisciplinary teams before peer worker(s) can be introduced, addressing negative attitudes and values towards IDUs and confronting the culture of the services and entrenched stigma and discrimination against IDUs and IDU peer workers;

- That the reason for needing peer workers in health services – that is the distrust and general stigma experienced by IDU within healthcare – can be the same reason why peer workers do not feel they can work in such environments; and
- At what point should a peer worker divulge client information (such as a client’s drug use) to other members of the multidisciplinary team especially when the consequences or impact of such drug use may have health implications such as hepatic or immune dysfunction during hepatitis C treatment but the peer worker and/or client may not be aware of such consequences (Norman, 2008).

The Centre for Harm Reduction (CHR) published a fact sheet, *The Value of Peer Education*, that summarises the inherent values and caveats when utilising peers in education/support roles. The paper states that “research shows that drug users will often more readily accept and trust information on drug related matters from their peers rather than from other sources” and “peers speak a language both verbal and unspoken that is completely unique to the drug using culture and their ability to communicate is crucial.” (Centre for Harm Reduction, www.chr.asn.au)

The CHR fact sheet also includes a number of cautions and caveats that highlight the importance of training and ongoing support for IDU peer workers and a recognition that IDU peer workers are often managing their own needs and issues in relation to drug use, hepatitis C, pharmacotherapies, etc. Some of the issues for IDU peer workers identified in the CHR fact sheet include:

- Difficulty keeping own drug use under control;
- Conflicts of being a professional health care worker and maintaining peer status;
- Occupational stresses associated with the demanding nature of the clients;
- Lack of supervision and support can affect self-discipline; and
- Lack of measurable outcomes that can prove frustrating (Centre for Harm Reduction, www.chr.asn.au).

The issues and questions raised both by the HLC project and the CHR fact sheet require more investigation if we want to access the benefits of IDU peer support for hepatitis C and maintain the effectiveness of peer workers. Clearly peer workers need to be part of an integrated and multidisciplinary team to be effective and accessible for clients but it will be difficult if not impossible for a peer support worker to be effective if

they are not being treated as a colleague and equal by other staff and do not have access to appropriate training and supervision. In developing models of access and service delivery that include peer support, we cannot simply pretend that stigma and discrimination against people with a history of injecting drug use does not occur in our services. Tackling the barriers to service access for people with a history of injecting drug use will involve an honest assessment of why these barriers exist in the first instance. Genuine partnerships with peer-based drug user organisations is a critical first step in undertaking the preparation work for integrated and multidisciplinary models of care that encourage and enhance, rather than undermine, peer support approaches.

d. Summary of Models to Improve Hepatitis C Access & Service Delivery:

In their document on *Models of Access and Clinical Service Delivery for HIV Positive People in Australia* the Australian Society for HIV Medicine (ASHM) and the National Association of People Living with HIV/AIDS (NAPWA) highlighted the absence of conclusive evidence at the international level to support the adoption of certain models or approaches over others. In particular they noted the absence of effectiveness and cost-effectiveness data at the level of HIV clinical services delivery and that programs targeting marginalised populations have frequently been pilot programs only, making conclusions about models difficult (ASHM and NAPWA, 2009).

While it is beyond the scope of this document to review the international literature on the relative effectiveness and cost-effectiveness of models of access and service delivery for hepatitis C, it is extremely unlikely that there would be conclusive data in this area as clinical service delivery for hepatitis C is poorly resourced both in absolute and comparative terms. As highlighted above, in the area of hepatitis C clinical and support services almost all of the programs targeting marginalised populations such as people with a history of injecting drug use have also been one-off or pilot projects resulting in limited conclusive data for building service models.

The ASHM/NAPWA HIV models paper also highlighted the need to take care in seeking to transpose clinical models from one context to another (ASHM and NAPWA, 2009). In this regard, even if some international studies do exist in relation to hepatitis C clinical services delivery and health outcomes, there would necessarily be questions about the applicability of such models in the Australian context due to differences in geography, economy, populations and health systems .

Despite these limitations, as already highlighted above we do have some positive findings from the evaluations

and outcomes of Australian pilot programs and developments in relation to existing service delivery models that can be used to assess the likely suitability of certain programmatic approaches in various contexts (Spina, 2007, McNally, 2009 and Norman, 2008). These initial outcomes can be coupled with assessments of existing hepatitis C service models and the models of preventative and primary health care, chronic disease management and peer support approaches as outlined above to develop a set of operating principles upon which new models of access and service delivery for hepatitis C can be based. These operating principles and practices include:

- Utilising empowerment-based and person-centred approaches;
- Building capacity for self-management and self-care – supporting people to manage their own health and conditions;
- Ensuring coordinated and integrated care – particularly across specialist, mainstream and community-based services and across the prevention/care continuum;
- Valuing effective communication - between service providers and between service providers and clients;
- Applying evidence-based policy frameworks, clinical care and management models;
- Adopting multi and inter-disciplinary team approaches to the provision of services and care;
- Including peer support as a fundamental component of integrated care models;
- Ensuring a properly resourced, trained and supported health and allied care workforce including the peer workforce;
- Supporting good health outcomes through safe and effective health information management systems; and
- Responding to the social determinants of health and other systemic barriers as part of developing comprehensive models of access and service delivery – including the impact of criminalisation, stigma and discrimination on health outcomes.

e. Impact of Health System Reform on Future Models of Access and Service Delivery for Chronic Hepatitis C:

In March 2010 the Australian Government released 'A National Health and Hospitals Network for Australia's Future' which sets out the 'National Health Reform

Plan' for far reaching and unprecedented reform to the Australian health system. The plan which has begun its progressive implementation from July 2010, outlines a major reorientation of both funding and policy responsibility for health care delivery in Australia. Under the revised system, the Australian Government will become the majority funder of hospital-based services (60 percent) and 100 percent funder of primary health services.

For almost a decade there has been discussion of the need to reform Australia's health system to reduce fragmentation in care between the acute (hospital-based) and primary health care systems particularly in the context of rapid growth of chronic illness associated with ageing population and the need for a greater focus on prevention (Cranny, 2010). In a recently commissioned report on the reforms to the health system developed for the Australian General Practice Network (AGPN), the following projections are made for health spending in Australia:

"The 2010 Intergenerational Report Australia to 2050: future challenges found that total government spending is projected to increase to 27.1% of GDP in 2049/50 with around two thirds of the projected increase expected to be on health. Spending on health will rise from 4% of GDP in 2009/10 to 7.1% in 2049/50 and the bulk of the increase will be on MBS, hospital services and the Pharmaceutical Benefits Scheme" (Cranny, 2010).

The need to shift to a greater emphasis on models of preventative and primary health care particularly in relation to the management of people with complex, chronic and long term conditions has also been the focus of key international reports. In its report on primary health care the World Health Organisation (WHO) found that countries with health systems focused on primary health care models produced better health outcomes for their populations (WHO, 2008). In this regard, the report commissioned by the AGPN states that it is not surprising that countries such as Australia and others including the UK, Canada and New Zealand are seeking to address the focus of their health systems and despite differences across these systems they have identified some common models and principles that are being recommended including:

- Planning around the needs of populations and communities and across the life span;

- Focusing on improving population health outcomes through prevention and addressing the causes as well as the consequences of ill health and disability including the social determinants of health;
- Putting the 'person' at the centre of the service system and providing support for people to 'take control of their own health';
- Increasing capacity to provide a wider range of care in the community including increasing access to multidisciplinary and team based models of care for people with complex and chronic illness and high long term care needs;
- Linking different service providers (and where relevant social care agencies) through local networks and partnerships that work together to assess and address local needs and that use common tools to support integrated and coordinated service provision for their clients;
- Adopting workforce structures that use the skills and competencies of the medical, nursing and allied health workforce effectively to provide integrated care for people and to address gaps in access and workforce shortages;
- Using commissioning and 'purchasing' approaches to address gaps in service delivery and market failures and to test innovation and new models of care; and
- Focusing on improving quality and measuring performance in primary health care.

(Cranny, 2010)

As part of achieving the above principles and outcomes the National Health Reform Plan commits to structural reforms such as the establishment of local hospital networks (LHNs) which will replace current organising structures such as the Area Health Services or Health Regions. The other main structural reform is the establishment of primary health care organisations (PHCOs) with the aim of coordinating and integrating access to care across acute and primary care services. With transfer of funding and policy responsibilities from the jurisdictions to the Commonwealth in total for primary health care and in large part for hospital services, there are still many questions about how this process will occur and what it means for existing health sectors and services including AOD, NSP and other population health and NGO services. Although it will take many years for the reforms to be properly 'bedded-down' with significant fluidity within the system in the meantime, basic aspects of the new system design are already being articulated in

key government reports and in this regard warrant some further discussion in a paper such as this which is seeking to advocate for new and/or improved models of access and service delivery in relation to chronic hepatitis C.

The PHCOs being proposed in the new structure are a completely new concept in Australian health care as they will be independent entities funded by, but existing outside government. It is expected that the boundaries for the PHCOs, or "Medicare Locals" (MLs), will largely evolve from the current Divisions of General Practice and are meant to be based around the needs of local populations and communities with strong links to the LHNs, local communities and other health services (Commonwealth of Australia, 2010). The MLs are meant to allow greater flexibility and capacity to plan and respond to local community need and ensure coordinated and integrated services across both primary and acute care. This approach aims to be more effective at addressing the needs of people with complex and chronic conditions in particular (Commonwealth of Australia, 2010).

There is little information at this stage on how the MLs will operate particularly in relation to accountabilities and performance measures but there is apparent capacity for MLs to be drawn from or include a range of services beyond general practice such as Aboriginal Medical Services, allied health services, NSP, AOD services, etc. How this might occur in practice however is not yet clear and there is currently a good deal of discussion about the relationship between existing health services and the proposed MLs including the degree to which MLs will or should be general practice focused. While it is possible in theory that the MLs could provide new opportunities to improve access to primary health care for people with a history of injecting drug use, this will depend on a range of design and development factors. Such factors include the nature of the approach used to assess the needs of local catchment populations, whether those assessments have the capacity to accurately identify the health needs of the highly marginalised as well as the mainstream population and whether the structure of the MLs will incorporate innovative, not just mainstream, models of access and service delivery.

The LHNs would similarly be based around boundaries of identified local populations and communities and should operate in a co-operative and co-ordinated relationship with the PHCOs/MLs. Although NSW has made some recent announcements on boundaries, there is still much to be decided about these new arrangements such as how the governance arrangements and boundaries for both the PHCOs/MLs and the LHNs will operate. This will need to include decisions on the size of local areas, natural catchments, populations and critical mass, cross boundary issues, boundary alignments and

issues in relation to specialities and general practice and electronic health records (Cranny, 2010). While it will take considerable time for many of these and other issues associated with the reforms to be adequately resolved and for the new system to be operational, from AIVL's perspective there are already a range of important questions emerging in relation to the proposed structure and function of the new system particularly for people with chronic hepatitis C and a history of injecting drug use.

While there are not necessarily answers to these questions at this stage, it is important to acknowledge the role of critical questioning in the implementation of the health system reforms. The significance of broad consultation with the existing primary health care sector (in its widest interpretation) and taking adequate time for planning and even piloting new approaches has been highlighted in a report on the unintended negative consequences of health care reforms in New Zealand (Gauld, 2008). While there are key differences (particularly in relation to hospital reform) there are also a range of important similarities in the process and approach to health system reform underway in Australia and New Zealand. The strong role of the political process in driving both the scope and pace of health system reform, the primary goal of establishing new population health-oriented primary health care organisations with the aim of improving access to primary health care services and an existing network of GPs that are independent, highly organised and well represented are just three of the similarities across the systems (Gauld, 2008).

The potential for unintended negative consequences being associated with the reform of the Australian health care system is very real. Taking note from the New Zealand experience, AIVL believes care needs to be taken at this early stage to ensure that the concepts of partnership, involvement of affected communities and consumer-centred health care are embedded in the new system. While we fully acknowledge that the process has only just commenced, AIVL already has concerns about the potential for a primary health care system that is dominated by clinical pathways and the 'medical model'. Already the language being used to describe service delivery approaches seems to be favouring an 'episodes of care' model rather than robust discussions about the merits of capitation or payment by person approaches (or other possible models) compared to measuring care in 'episodes'. These decisions will not only have implications for funding and how much consumers may pay for health care, but AIVL is also concerned about how an 'episodes of care' approach will achieve the stated policy outcomes of providing more co-ordinated, accessible and integrated care across the primary health and acute care sectors (Commonwealth of Australia, 2010).

For people with chronic hepatitis C infection who also have a history of injecting drug use, the capacity of the health system to provide comprehensive, integrated and holistic care in relation to clinical and non-clinical needs is paramount. In this context, AIVL believes there is a need for discussion on the definition of 'episodes of care' being used at this early stage in the reform process – what will characterise an 'episode' of care and what will 'care' mean in a system primarily organised around 'Medicare Locals' and 'Local Hospital Networks'? Will an 'episode of care' be a course of hepatitis C treatment or does it describe a co-ordinated and multidisciplinary approach to supporting a person with chronic hepatitis C to manage their own health with or without treatment? Will an 'episode of care' include health promotion and harm reduction activities such as needle and syringe programs (NSPs) and if it does, will it incorporate the comprehensive range of services, education and support provided through primary and in particular peer-based NSPs, or will it only recognise the act of distributing injecting equipment – that is giving someone a new needle & syringe?

In short, the question comes down to what aspects of service delivery will be valued as an 'episode of care' and therefore what types of services and health professionals will be valued by the system? Does a system that focuses on 'episodes' rather than 'people' have the capacity to take account of the broader social context of people's lives and health and provide access to the range of clinical and non-clinical services and support that are needed for complex and chronic conditions such as hepatitis C? Linking to other non-clinical services are mentioned within the reform policy documents but there does not appear to be concrete discussions about how this principle will be operationalised within the proposed model. AIVL is concerned that such services can easily get lost in a model that is dominated by clinical services and settings. It is one matter to outline lofty reform objectives about expanding access to primary health care, linking service providers through local networks and partnerships and co-ordinated and integrated health care but how is this achieved in practice within the proposed system? How does a system focused around 'episodes of care' ensure it is person-centred, responsive to local populations and communities and available across a person's life span as indicated in the reform objectives?

Even if the definition of 'episodes of care' adopted is sufficient to encompass access to a range of service providers and types of care, there is still a need to ensure the system has the capacity to provide 'consistent' levels of access and service delivery and does not result, as it has been described in the New Zealand case, in "the creation of a labyrinthine funding and organisational system with variable capacity to deliver on the government's reform objectives" (Gauld, 2008).

For people with a history of injecting drug use it is critical that the new system is person-centred and in this regard easy to navigate and engage with, is affordable for all and capable of providing a consistently high level of access and service delivery. There are many examples in the current health system where these ideals are not met, even in part, and it is because the health system is too often experienced by the highly marginalised as intimidating, judgmental, inconsistent and costly that many avoid contact unless it is critical. These fundamental problems will not be addressed by the current reform of the health system unless the process reform specifically confronts and addresses the way the most marginalised in our community currently experience the health system. A focus on efficiencies and cost-effectiveness models alone will not achieve this outcome.

In addition to the concerns outlined above, there are also questions about how the proposed models will manage existing relationships with clinicians outside of the yet to be defined boundaries for the MLs and LHNs. People on opioid pharmacotherapies who are prescribed through general practice have existing and often long term clinical relationships with a particular prescriber. If an individual's prescribing arrangements fall outside of the yet to be set boundaries for MLs and LHNs how will this be managed – will there be adequate cross-boundary flexibility? Will there be sufficient authorised prescribers within each ML and how will this be achieved when the current system is already struggling with shortages of trained and authorised prescribers and the impact of an ageing GP prescriber population? (Ritter, 2009)

Principles such as linking service providers, using common care planning and support tools, electronic health records and better use of workforce skills and competencies are meant to address current problems within the system. It also needs to be understood however that the sudden introduction of common care plans, links between service providers and electronic health records can act to further intimidate and marginalise people with a history of injecting drug use from the health system rather than improve access and service delivery. Such systems can work to improve access to and the quality of services for relatively empowered health consumers with a degree of confidence in the health system, patient confidentiality, informed consent, etc. Regardless of the intentions of such systems, they can act as a deterrent however for those who have real and/or perceived fears about how such systems might impact on their access to services and how personal information could be used against them resulting in poorer treatment and less access.

There are also important questions about how services and approaches that are currently part of what is understood as the 'broader primary health care sector' such as Aboriginal Community Controlled Health Services, community health centres and other NGO services will be comprehensively included in the new system. How will NGO-based health services that are currently provided at the jurisdictional level yet earmarked for 'transitioning to the Commonwealth' be protected and maintained in this process? In particular how will this be managed in a consistent way across jurisdictions and ensure ongoing access and service delivery? Resolving these issues quickly and effectively is critical particularly in relation to groups who are broadly acknowledged as having poor access to health care and for whom hepatitis C prevention and management is of significant growing concern such as Indigenous people with a history of injecting drug use. AIVL believes there are also important questions about the role and delivery of health promotion, prevention, AOD, harm reduction, peer education and community development programs. All of these programs are currently all but missing from the reform agenda outside of broad references to the National Preventative Health Partnership and the National Health Prevention Agency – neither of which have to date indicated that hepatitis C or illicit/injecting drug use is a priority focus.

These issues require careful consideration as they involve a range of services and programs (particularly NSP and peer-based organisations and programs) that available evidence and the *National Hepatitis C Strategy* have identified as being highly effective and cost effective in relation to preventable chronic diseases such as hepatitis C, HIV, etc (NCHECR, 2009 and DoHA, 2010). Further it also involves services particularly Needle & Syringe Programs (NSPs) and opioid pharmacotherapies services that are delivered in a range of settings across the hospital and primary health sectors and in this regard represent a unique opportunity to ensure the new system does reflect proposed models and principles of integrated and increased access to quality care. AIVL believes there is insufficient discussion about where critical population health services such as NSP and opioid pharmacotherapy will be situated and the relative merits of the various options available within the new system including whether such services are coordinated at the federal or jurisdictional levels. More discussion is also needed about how a continuum of care for prisoners particularly in relation to hepatitis C prevention, management and treatment is addressed with corrections health being quarantined from the reform process.

AIVL acknowledges that it is very early days and that any reform process presents important opportunities as well as potential threats. Despite this acknowledgement however, the apparent lack of structured opportunities for consultation with the broader health sector, particularly those outside of the COAG process, needs to be addressed as a matter of urgency. People with chronic hepatitis C and a history of injecting drug use will be significantly affected by the reform of the health system but are currently not being adequately consulted on the reform process or their future health care needs. We are not alone in this regard and the 'National Campaign for Consumer-Centred Health Care' has recently formed specifically in response to a perceived imbalance in the Australian health reform debate. A recent discussion paper produced by a coalition of NSW community-based NGOs with a specific focus on BBVs is further evidence of the desire for greater involvement and consultation in the reform process at this early stage (ACON et al, 2010).

AIVL acknowledges attempts to engage with broader stakeholders through the recent dissemination of the national reform plan and through the 'yourhealth' website but information will not be an adequate substitute for actual consultation in the longer term. Key stakeholders particularly those groups in the populations directly affected by complex and chronic health conditions and the non-government community based sector must be engaged as partners in the reform process as getting 'buy-in' into the new system will be critical for implementation. Given that a lack of consultation with the broader primary health care sector and inadequate planning and piloting of initiatives has already been identified as factors that some believe have reduced the effectiveness of the New Zealand primary health care reforms (Gauld, 2008), AIVL believes better stakeholder engagement needs to be addressed sooner rather than later.

As outlined above, the reform of the Australian health system is fundamental and unprecedented. Added to this is the fact that planning and implementation have only recently begun and while there is already a good deal to discuss, the nature of the process is such that some of these early articulations of the new system are likely to shift and evolve. This paper is not primarily focused on the health system reforms but does need to have this process firmly in sight for the remainder of the document which will focus on barriers to access and service delivery in relation hepatitis C specifically for people with a history of injecting drug use. A number of issues have been identified above as being potential concerns in so far as they could act as barriers to access and service delivery under the new health system. If we hope to prevent

the realisation of these barriers and achieve the stated policy objectives for health system reform, a greater understanding of what is currently preventing people with a history of injecting drug use accessing services and care in relation to hepatitis C is required. ■

4 Barriers to Access and Service Delivery for People with Chronic Hepatitis C and a History of Injecting Drug Use

Addressing barriers to access and service delivery for people with chronic hepatitis who have a history of injecting drug use cannot be achieved through approaches that focus on the delivery of treatment and the development of clinical pathways alone. We need models of care that are comprehensive, compassionate and most of all are proactive about addressing both the systemic and structural barriers that prevent many of us achieving even the most basic levels of health empowerment and health literacy. Any approach that simply seeks to provide ‘more’ treatment and clinical services without addressing the reasons why people are not accessing treatment and clinical services now will do very little to reduce the long term impacts of chronic hepatitis C infection (either at the individual or community levels) and will not lead to improvements in access and service delivery for our community.

a. Social, Legal, Economic & Cultural Determinants of Health

AIVL believes it is impossible to develop effective models of access and service delivery for people with chronic hepatitis C infection and a history of injecting drug use without first gaining a better understanding of the contexts in which people live and the factors that shape their health and wellbeing. At the international level there is now an extensive literature on social factors that can determine the health of both individuals and particular groups within society particularly among marginalised populations such as people with a history of injecting drug use. These social factors are referred to as the ‘social determinants of health’ in order to reflect their direct and indirect roles in shaping health at the macro and individual levels. (Marmot, 2006)

The World Health Organisation (WHO) defines the social determinants of health in the following way:

“The social determinants of health are the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries”

(WHO, 2010)

Further the WHO Commission on the Social Determinants of Health opened its interim statement on building a global movement for health equity with these words:

“Strengthening health equity – globally and within countries – means going beyond contemporary concentration on the immediate causes of disease. More than any other global health endeavour, the Commission focuses on the “causes of the causes” – the fundamental structures of social hierarchy and the socially determined conditions these structures create in which people grow, live, work and age – the social determinants of health. The time for action is now: not just because better health makes economic sense, but because it is right and just.” (CSDH, 2007)

The above approach to understanding health inequities is highly relevant for people with a history of injecting drug use and particularly while people are in active injecting drug use and/or on pharmacotherapy

programs. It should be stated at the outset however that the health inequities experienced by people who inject drugs often have long term and even life-long impacts that require ongoing understanding and response even if the person ceases injecting. For this reason AIVL has chosen to speak about people with a history of injecting drug use but with the clear understanding that individuals can and frequently do carry a greater burden of health inequities at different points in their lives. AIVL also recognises that there can be multiple and confounding social determinants of health that can disproportionately affect people with history of injecting drug use from Aboriginal and Torres Strait Islander backgrounds and CALD backgrounds. This is evidenced by the fact that although illicit drug use occurs within all cultural and socio-economic groups in society, drug-related injury, illness and death are disproportionately higher among people living in poverty and those from Indigenous and CALD backgrounds (Galea and Vlahov, 2002, Ward, 2010, Maher, 2004).

The processes of international relations and national and local legislative and policy development shape our society not just in terms of how we are organised but also in relation to social hierarchy, public policies and cultural norms and social relationships. This “universe of social factors” creates the social environment in which people live and also defines their likelihood of good health and their vulnerability to poor health. Research suggests that there may be a number of ways in which social determinants impact on health but there is general agreement in the literature that “specific social factors play a role in determining health, indirectly or directly, either detrimentally and protectively” (Galea and Vlahov, 2002). For example it is now well accepted that the health of people who inject drugs has a direct relationship to their social environment and that the drugs people use and how they use them, particularly in terms of drug-taking behaviours and individual risk practices are not independent factors, but are a product of their social environment (Palepu, 1999).

Too often when the issues of injecting drug use and health are examined the focus does not shift beyond the drug-taking behaviour itself and/or individual risk practices that are seen as being directly responsible for poorer health outcomes among people with a history of injecting drug use. The limitations of this approach to understanding drug user health and health inequities is captured by Galea and Vlahov in their work on social determinants and the health of drug users:

“Behavioural research fits a traditional epidemiologic risk factor model. Although this work has guided public health interventions

and some have been successful in reducing the burden of disease among IDUs, it does not recognize the fundamental social circumstances that shape behaviour and ultimately influence the health of drug users. Under-specification of the range of factors associated with risk behaviours and health outcomes can bias epidemiologic inquiry and limit the potential scope of successful interventions.”(Galea and Vlahov, 2002)

Although specific drug-taking behaviours and individual risk practices undoubtedly contribute to adverse health consequences, they do not on their own explain the degree of health disparity routinely documented either between individual drug users or between drug users and the rest of the population. For example while there is not a significant body of research into this issue as yet, there are ongoing discussions among researchers and public health advocates about whether differences in injecting drug use practices and risk behaviours might explain the disproportionate level of hepatitis C and other BBVs among Aboriginal and Torres Strait Islander people with a history of injecting drug use. Despite a lack of adequate Australian research exploring this theory, research from the US on the reasons for higher levels of HIV infection among African American IDUs strongly suggests that injecting drug use risk behaviours alone cannot fully explain the disproportionate burden of disease and that the higher HIV rates apply even after data is adjusted for drug taking and other risk practices (Vlahov, 1990 and Fullilove, 1992). Further, research from Vancouver also found that although individual practices play a role, social determinants were among the most significant predictors of needle-sharing behaviour among IDUs participating in the study (Strathdee, 1997).

As illicit drug use itself is a product of the social environment, particularly of public policy and law, it is logical that the behaviours and risk practices that can be associated with illicit drug use and can led to adverse health outcomes would themselves be shaped and exacerbated by the larger social context. The impact and role of ‘social factors’ and ‘social setting’ on the risk factors for BBV infection is well documented in research (Southgate, 2003). In particular the adverse impact of poverty, homelessness, poor access to services, stigma and discrimination and incarceration on the health outcomes of people who inject drugs is highlighted (Galea and Vlahov, 2002). Given that these social factors and settings also have a negative impact on the health outcomes for other individuals and groups in the population it is reasonable that they may go some way

to explaining the level of health inequities among and between people with a history of injecting drug use. Despite this fact, the public discourse on health and disease remains focused on 'life-style' approaches to disease prevention (Raphael, 2008) with our approach to addressing hepatitis C and injecting drug use an obvious case in point.

Understanding the relationship between the 'social setting' and injecting practices is also an important part of contextualising risk. One of the main difficulties with framing individual or even group injecting risk practices as 'causes' of poor health rather than 'consequences' that are linked to a broader social environment, is that it does not recognise that 'risk' is not a static or objective construct. Risk in itself can only be understood within its social context. The way that people understand and quantify both absolute and relative levels of 'risk' is always with reference to the absence and presence of other risky and protective factors in the social setting in which the drug use is occurring (Southgate, 2003). For example the act of injecting itself is often characterised as a high risk practice but in reality the degree of risk associated with injecting is affected by myriad social factors that can act to significantly increase or decrease the level of risk associated with the practice of injecting.

Some of the factors that can have a significant impact on the degree of risk associated with injecting illicit drugs could include: the illegal source and unknown quality of the drugs being used, the physical environment in which the use is occurring, whether there is access to new injecting equipment, who else is present or nearby and who those people are (are they police, NSP workers or IDU peers), if other IDU peers are present are they also injecting, do they have BBVs, do they know how to protect themselves and others from BBVs, overdose, etc? The importance of social setting to risk and therefore the likelihood of adverse health outcomes are further highlighted by considering an alternative social context such as the use of a range of injectable opioids and amphetamines in the clinical setting. By applying the same set of factors above we can arrive at a very different (almost opposite) assessment of the level risk associated with injecting if it involves using a drug acquired through a legal source and of known quality and dosage, injected in a sterile or clean environment, with adequate access to new injecting equipment and with administration occurring by or under the supervision of people who are trained and fully equipped to respond to adverse outcomes.

Despite some research acknowledging the importance of placing drug use and injecting risk practices in a social context, the majority of existing research does not seem

to take the obvious next step of asking "do all social factors shape health in the same way or to same degree"? Research into the social determinants of the health for people with a history of injecting drug use does go as far as to acknowledge that there are a range of inter-related and often inextricably entwined social factors that act as determinants of health and health inequities. While this approach is useful in understanding factors that can lead to health disparities between individual drug users and between different groups of drug users, it is not sufficient to explain the health inequities between IDUs and the rest of the population. When it comes to identifying, as WHO has stated, the "causes of the causes" - those factors that above all else determine the health of people with a history of injecting drug use and their degree of vulnerability to poor health, AIVL believes that there are 'determinants of the determinants' and these are stigma and discrimination and the impact of illegality and criminalisation.

Social theory would suggest however that these 'determinants of determinants', that is stigma and discrimination and illegality and criminalisation, cannot merely be understood as a 'hierarchy of social determinants', but rather are more accurately described as 'structural violence' (Treloar, 2010). The concept of structural violence was first coined in the 1960s and refers to a form of violence which is based on the systematic ways in which social structures and institutions can harm people by preventing them from meeting their basic needs. Galtung in his seminal work on this issue describes structural violence as the "violence that is built into the structure and shows up as unequal power and consequently as unequal life chances" (Galtung, 1969). Further work on the issue of structural violence also suggests that its outcomes in the form of death, disease and disabilities are due to the stress, shame, discrimination and denigration that is associated with being viewed as unequal (Gillian, 1997).

In this way, structural violence as it relates to people with a history of injecting drug use can be said to underpin and act as a mechanism to exacerbate factors that are traditionally considered to be the social determinants of health. For example, the current drug policies and laws that make injecting certain substances illegal also isolate people from society, perpetuate stigma and discrimination, label people as criminals, force people to take risks and either exacerbate or can lead to poverty, lack of education, lack of employment, homelessness, incarceration, etc. The way that structural violence operates in the lives and on the health of people with a history of injecting drug use is exemplified in the results of the heroin prescription programs in Europe. These programs have demonstrated that removing the systemic or institutionalised harms of illegality, criminality and the

extreme levels of stigma and discrimination associated with illicit heroin use results in people successfully addressing other social factors that can have an adverse impact on health outcomes such as education levels, unemployment, poverty, homelessness, recidivism, and importantly access to and uptake of health services (Lintzeris et al, 2009).

i. Impact of Stigma and Discrimination:

Erving Goffman's work on theorising stigma describes stigma as "an attribute, behaviour, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one." Goffman goes further to define stigma as a "special kind of gap between virtual social identity and actual social identity". Virtual social identity is the assumed characteristics and attributes we transpose onto people when we first meet them whereas actual social identity is the characteristics and attributes someone is proved to possess which may be quite different to our assumptions about a person (Goffman, 1986). In this way, Goffman suggests that stigma acts to "spoil normal identity" and reduce people from being a whole and usual person to being a tainted and discounted one (Goffman, 1986).

It is not difficult to understand how the stigma and discrimination routinely experienced by people with a history of injecting drug use can profoundly affect people's health status and make them extremely vulnerable to poor health. Research with injecting drug users has demonstrated the links between policy and practice and community and societal attitudes towards injecting drug users and the subsequent negative implications for IDU health. (Tindal, 2010) The shame and stigma associated with injecting illicit drugs forces people away from information, support and services and isolates them from family, friends, crucial health and social services and the rest of society. For many people with a history of injecting drug use, the long-term effects of being locked outside of mainstream society are; serious health problems, poverty, unemployment, poor levels of education, family and community breakdown and in many cases, premature death. Further, stigma has been directly associated in research with high-risk injecting practices resulting in HIV and hepatitis C infection, high levels of drug dependence, repeated incarceration, severe economic disadvantage and homelessness (Southgate, 2003).

There is an inextricable link between injecting drug use related stigma and discrimination and hepatitis C related discrimination. Both the NSW Anti-Discrimination Board

Inquiry into Hepatitis C Related Discrimination in 2001 and the Senate Community Affairs Reference Committee on Hepatitis C and the Blood Supply in Australia in 2004, found that hepatitis C is a highly stigmatised condition, that hepatitis C discrimination is rife and that *discrimination in relation to injecting drug use lies at the heart of both of these situations* (NSW ADB, 2001). Indeed the NSW Anti-Discrimination Board Inquiry concluded that strategies designed to address discrimination against people on the basis of their past, current or assumed drug use must be an integral part of responding to hepatitis C related discrimination."

The *C-Change Report* undertaken by the NSW Anti-Discrimination Board in 2001 was at the time, and remains now, the most comprehensive examination of issues relating to stigma and discrimination among those most affected by hepatitis C in Australia. Further work on this issue was also conducted in the *3D Project – Diagnosis, Disclosure, Discrimination & Living with Hepatitis C* published in 2003 (Hopwood and Treloar, 2003). Included in the recommendations and conclusions of the C Change Report are the following points:

- *Hepatitis C is a highly stigmatised condition and... discrimination against people with hepatitis C is rife.*
- *Health care settings were the most commonly reported context for hepatitis C discrimination.*
- *Discrimination often has a profound impact on the lives of people with hepatitis C; it frequently has damaging health, financial, social and emotional consequences both for people living with hepatitis C and the community. The experience of discrimination acts as a deterrent to people accessing the health system, with all the consequences this brings for the health of people with hepatitis C and the community.*
- *The fear of stigma and discrimination can lead people who believe they might already have contracted hepatitis C, to be reluctant to seek testing and treatment for hepatitis C.*
- *Societies have shown a distressing record of treating people with particular diseases as outcasts and denying them fundamental human dignity (NSW ADB, 2001).*

Findings from the *3D Project Report* include:

- 27.8% reported experiencing discrimination from a health care worker other than a doctor;
- 12.9% experienced discrimination from a doctor;
- 12.7% reported being refused medical treatment due to hepatitis C status;

- 45% said discrimination had negatively affected their emotional health; and
- 35.7% said their physical health had been negatively affected by discrimination (Hopwood and Treloar, 2003).

A conclusion reached by the *3D Project* was that “hepatitis C related discrimination occurs in a variety of social domains and is especially salient for people identified as, or assumed to be, injecting drug users” (Hopwood and Treloar, 2003). A paper delivered to the 5th Australasian Viral Hepatitis Conference (Sydney 2006) by Daniel Tarantola stated that:

“Discriminatory actions do not only amount to violations of human rights, but also to unsound public health practice as they act as a deterrent to access early diagnosis, support and prevention and treatment services” (Tarantola, 2006).

And mentions:

“...the nefarious effects hepatitis C markers can have on people’s access to care and other health and social services and, as importantly, on human health, welfare and dignity” (Tarantola, 2006).

Unfortunately, in the many years since the *C-Change* and *3-D* reports were published there has been little specific work done to address the issues identified or the recommendations made. This is of particular concern because the *C-Change Report* highlighted the systemic and entrenched nature of the problem across all levels of society but in particular in healthcare settings, employment, the criminal justice system and the general community including the media (NSW ADB, 2001). The impact of stigma and discrimination on the health and lives of people with a history of injecting drug use is significant. Although research in this area is limited, on the occasions they have been asked, people with a history of injecting drug use routinely identify stigma, discrimination and fear of poor treatment by health system as the main reasons they do not access primary health and other services including hepatitis C clinical services (Aitkin, 2002).

In the *Barriers and Incentives to Drug Treatment for Illicit Drug Users National Research Project* more than half the participants reported that they had been discriminated against by family (63%), staff at pharmacies (63%), friends (62%), doctors/nurses (54%) and a significant number mentioned discrimination by partners (37%), other health

workers (36%), landlords (36%) and workmates (34%) (Treloar, 2004). So widespread is the problem of drug use-related stigma and discrimination, that anecdotal reports indicate that many individual drug users live with extremely painful, debilitating and even life-threatening conditions rather than seeking out treatment from health services including hepatitis C prevention, diagnosis and treatment services.

Indigenous drug users, drug users from CALD backgrounds and drugs users with mental health issues are among the groups that live with multiple layers of stigma, discrimination and human rights violations. Poor attitudes among service providers, the media and the general community towards these groups results in increased vulnerabilities and levels of social exclusion including significantly higher rates of homelessness, incarceration, unemployment, poverty, social isolation and chronic health problems. (DoHA, 2005). Indeed, research shows that rates of hepatitis C infection are between 3 and 13 times higher among Indigenous people with a history of injecting drug use than their non-Indigenous peers with variations between jurisdictions and age groups (NCHECR, 2009a).

The *National Hepatitis C Strategy* specifically highlights poor access to mainstream services as one of the main barriers to effectively addressing hepatitis C related issues among Aboriginal and Torres Strait Islander people (DoHA, 2010). The *National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy 2010-2013* also identifies a number of factors that place Aboriginal and Torres Strait Islander people who inject drugs at risk of hepatitis C including a lack of access to culturally appropriate services, discrimination and stigmatisation, concerns about confidentiality in service provision and a lack of support to address BBV issues in the broader context of their health and lives (DoHA, 2010b).

Indigenous people who inject drugs have been identified by AIVL and the relevant national strategies as needing specific and priority focus to address the disproportionate affect BBVs are having on this group of people within our community. Higher morbidity and mortality rates, poorer access to health and social services and supports and much greater incarceration rates all suggest that hepatitis C is likely to have a significantly higher impact on Indigenous Australians with a history of injecting drug use. There is an urgent need to address the impact of high levels of stigma and discrimination on Indigenous drug users which underpins the higher burden of disease among this group.

There is also a significant need to address disproportionate rates of hepatitis C and other BBVs among people with

a history of injecting drug use who are of Asian cultural background. Research with this group has shown higher rates of infection and increased risk of transmission associated with Asian ethnicity, recent incarceration, public injecting and duration of injecting (Maher, 2004). These findings suggest there is a need not only for increased peer education/support for and by Asian people with a history of injecting drug use but also an urgent need for systemic change that seeks to increase access to health services including reducing barriers caused by stigma and discrimination and developing alternatives to incarceration.

The *National Hepatitis C Strategy 2010-2013* has identified “minimising the personal and social impact of hepatitis C” as one of three overarching goals for the life of the Strategy. The main objective of this goal is to “reduce hepatitis C related stigma and discrimination in health care settings” (DoHA, 2010). Further, the Strategy also acknowledges that the social ramifications of hepatitis C infection particularly the stigma and discrimination associated with hepatitis C and the barriers it creates to individuals accessing prevention education, care, support and treatment, underpins all activities within the Strategy (DoHA, 2010).

A market research report recently commissioned by AIVL reinforces the fact that discrimination against people with a history of injecting drug use is widespread and, in many cases, deemed acceptable by people without a history of injecting drug use. The market research found that “many participants from the general public believe that marginalising people who inject drugs is positive for society as a whole...” and many openly admitted to discriminating against people who inject drugs. Essentially, stigma and discrimination toward people who inject drugs is perceived to be a useful prevention strategy among a large portion of the general public participating in the focus groups. It was seen as a means of controlling the problem and importantly, the general public in the focus groups did not identify stigma and discrimination towards injecting drug users as inappropriate. It is also worth noting that discrimination was on the basis of both actual and presumed injecting drug use and members of the general public admitted to having little or no actual contact with people who inject drugs (Parr, 2010).

Negative attitudes towards people with a history of injecting drug use were not limited to the general community:

- *Younger respondents in the medical professionals group tended to believe that a stigma should exist for people who inject drugs;*
- *Some medical professionals tended to have the same views [as the general community] in regards to a physical stereotype about people who inject drugs; and*
- *In the current social and legal environment, the general public and many medical professionals feel that stigma and discrimination toward people who inject drugs is an important means of containing the practice and should exist (Parr, 2010).*

While AIVL is not at all naive about the significant challenges that we are seeking to take on in tackling the issues identified through the market research, we equally do not feel that we have an option in relation to ‘whether’ as a sector or community we try to take those next steps or not. From the perspective of halting the transmission of hepatitis C and reducing barriers to prevention and treatment access, to do nothing, even if the challenges are significant, is not an acceptable option either for those most affected by hepatitis C or for the community as a whole. This is also supported by the Anti-Discrimination Board of NSW that stated:

“Protection of the human rights of people with hepatitis C, and those most at risk of infection, particularly people who inject illicit drugs, is critical to an effective response to hepatitis C” (NSW ADB, 2001).

AIVL believes that until we address some of the fundamental issues that underpin IDU related stigma and discrimination we will continue to see people with a history of injecting drug use disproportionately affected by preventable diseases, experiencing unnecessary levels of drug related harm and routinely dealing with unacceptable barriers to treatment and basic health and social services. This is supported by research into the theory of stigma and discrimination and the experiences of injecting drug users in Australia which concluded that:

“... redressing the negative effects of stigma requires political will, financial support, increased community commitment and a better understanding of the links between the social determinants of health and the poor health status of injecting drug users. Without reducing stigma of injecting drug users the health of this marginalised population is likely to get worse, which will have broader negative population health effects” (Tindal, 2010).

As the issues above highlight, actual and assumed injecting drug use behaviour underpins the vast majority of hepatitis C related stigma and discrimination. It is

also clear from the market research that the majority of discrimination towards people who inject drugs (and therefore those most affected by hepatitis C) is driven by stereotypes, misinformation and a process of dehumanising drug users particularly through the media. The question remains however, what is at the basis of the attitudes and values that lead to these dehumanising levels of stigma and discrimination against people with a history of injecting drug use? We have already identified that when it comes to understanding the drivers of poor health and vulnerability among people with a history of injecting drug use it is necessary to move beyond the concept of the social determinants of health and to consider the impact of structural violence - the systematic ways in which social structures and institutions can harm and exclude people. But what explains the willingness of many in society to view such treatment of people with a history of injecting drug use as acceptable and even actively encourage it? To answer this it is necessary to consider a further question "is there a structural driver of stigma and discrimination against people with a history of injecting drug use?".

ii. Impact of Illegality and Criminalisation:

"Criminalisation of behaviour is most pronounced in the case of injecting drug users, which is a barrier to access prevention measures and treatment, as well as information. Historically society has dealt with diseases by demonising 'vectors of infection', such as the plague, leprosy, cholera and polio – this response exposes deep-rooted shame and fears associated with contagion, illness, pleasure and death. There is an even more potent ingredient of blame in the case of injecting drug use, [and is] therefore the most resistant form of discrimination." (Watchirs, 2010)

Approximately 10 years ago, the member states of the United Nations including Australia convened for a special UN assembly where it was agreed to work towards achieving a "drug-free world" within the decade. Member states agreed to undertake appropriate measures to eliminate or reduce the supply of and demand for illicit drugs and psychotropic substances. In the years since this UN special assembly, countries across the world including Australia have continued to invest large amounts of resources in reducing the supply of illicit drugs and as part of this approach continued to strengthen drug control policies and laws (OSI, 2009). The combined effect of all of this activity however has not been the

creation of a "drug-free world" or even steps towards it. Instead, the head of the UNODC and many other highly credible bodies have begun to admit that drug control measures have had significant unintended consequences particularly for those who have borne the brunt of this "war on drugs" – that is people who use or have used illicit drugs. Indeed too often the "war on drugs" has really been a "war on people" and has resulted in high rates of preventable disease, increasing levels of imprisonment and untold human rights violations. As the Open Society Institute states:

"... the question is not just whether a drug-free world is possible, but how many violations of human dignity and ethical conduct are seen as acceptable in the effort to achieve it. How can drug control conventions aimed at "reducing human suffering" be permitted to excuse so much hardship and humiliation? Today, and in the next decade, the goal should be to achieve total elimination or significant reduction in these unconscionable abuses committed in the name of drug control." (OSI, 2009)

For the reasons outlined above, AIVL believes that no discussion of the existing barriers to access and service delivery for people with chronic hepatitis C and a history of injecting drug use would be complete without an examination of the impact of the current drug control laws on health and wellbeing. The process of criminalisation associated with illicit drug use causes significant direct and indirect barriers to people's ability to manage chronic hepatitis C infection. This is supported by research in Australia which noted that although the study was focused on issues relating to access to hepatitis C service delivery, once the participants were comfortable and secure with the peer counsellor they frequently steered discussions in the direction of a broader range of problems they viewed as compounding or creating barriers to hepatitis C management including legal issues, housing problems, financial difficulties, etc (Aitkin, 2002). Anecdotal reports from people with a history of injecting drug use and drug dependency also confirm the ongoing pressure of having outstanding warrants, legal matters, court appearances and imprisonment as some of the factors that have led people to 'de-prioritise' their health generally and issues like hepatitis C in particular (Peer report).

In a recent and unprecedented article published in the British Medical Journal, leading medical and policy experts openly called for an end to the illegality of drug use and criminalisation of drug users through a process

of structural change including a review of national drug laws and policies (BMJ, 2010). Although the BMJ article was focused primarily on HIV prevention, the concepts, principles and urgency equally apply to other serious health issues for people with a history of injecting drug use particularly chronic hepatitis C. The article identifies the need to shift to regulatory models to control drug markets in order to reduce the health and social harms associated with the current drug laws and policies (BMJ, 2010). The need to both review and reform the current drug control laws and policies has also been identified as one of the priority actions in the recently released national hepatitis C and national HIV strategies. The *National Hepatitis C Strategy 2011-2013* states there is a need to 'harmonise' drug control laws with public health policies and outcomes to create a better social and legal environment for addressing hepatitis C (DoHA, 2010).

Despite significant thinking and writing on the social determinants of health, there has been comparatively little investigative work into the disproportionate impact of illegality and criminalisation on the health of people with a history of injecting drug use. Research on the social determinants of health in relation to injecting drug users for example, frequently identifies incarceration as an important social factor relating to IDU health but rarely seems to go further to explore the 'drivers' of that incarceration for IDU. The question needs to be 'why are IDU being incarcerated in the first place?' While incarceration can undoubtedly act as a social determinant of health for people with a history of injecting drug use, the nature of imprisonment means that it cannot be separated from the set of social conditions from which it draws its power and authority. In this regard, incarceration is simultaneously an independent determinant of health and, a 'consequence' of the current social policy environment that deems certain substances as illegal and criminalises those who use them – a process of structural violence.

The importance of viewing incarceration among people with a history of injecting drug use as a 'consequence' of illegality and criminalisation is supported by a review of current data in Australian prisons. Although it is difficult due to the wide variety of potential offences to identify at any given time the percentage of prisoners who have been convicted of 'drug-related offences' rather than 'drug offences' per se, there is a range of data regularly collected from a number of correctional facilities across Australia that does provide some insight into the relationship between illicit drug use, crime and imprisonment including:

- In 2007, sixty-one percent of adult detainees reported obtaining illicit drugs in the past 30 days;
- Forty-four percent of adult detainees reported that they had taken drugs prior to committing at least one of the offences for which they were charged;
- Fourteen percent of adult detainees said they were looking for drugs prior to arrest;
- Sixty percent of male adult detainees who had a violent offence as their most serious offence tested positive for at least one drug, compared with seventy-three percent of female detainees with a violent offence as their most serious offence;
- Forty-two percent of adult detainees who tested positive for at least one drug attributed at least some of their offending to their drug use (excluding alcohol); and
- Detainees who reported using drugs illicitly in the past 12 months were more likely to have a higher average number of charges in the past 12 months, compared with those who did not use drugs - 2.5 charges and 1.3 charges respectively (AIC, 2010).

The implications of this data suggests that strategies aimed at removing the illegality of drug use and the associated process of criminalisation would significantly reduce overall levels of incarceration. Diversionary schemes which 'divert' offenders away from prison into non-custodial arrangements which can include compulsory AOD treatment is another strategy that has been adopted in Australia in order to reduce levels of incarceration. While diversionary schemes are discussed in more detail below, it is important to note that diversionary schemes do not necessarily remove the process of criminalisation. With the exception of police diversion for cannabis which in some states and territories now includes civil rather than criminal penalties, diversion is offered as an 'alternative' to a custodial sentence for a criminal offence for which charges have been laid and/or a conviction upheld. This is particularly important in relation to injecting drug use which by definition involves more serious drug and drug-related offences which are often outside of the parameters of police discretion/diversion.

There are many ways in the Australian context in which illegality and criminalisation in relation to injecting and illicit drug use can be seen to be acting as a form of structural violence against people with a history of injecting drug use. For example, Australia has an increasing per capita rate of imprisonment (AIC, 2009), with new prisons being built across country and as identified above, high levels of incarceration among

people with a history of injecting and illicit drug use. Rates of Indigenous imprisonment are 17.2 times higher than the non-Indigenous population (AIC, 2009) and drug related offences are a significant factor among both Indigenous and non-Indigenous populations. The above factors are being driven by the increasing emphasis on law and order within the community with 'net-widening' exercises such as increased police powers, new search and seizure laws, sniffer dogs on public transport and the introduction of mandatory sentencing and truth in sentencing for certain drug offences in a number of jurisdictions. In Australia having been in prison is an independent risk factor for hepatitis C infection (Maher, 2004) and national surveillance is showing increasing HIV rates among new prison entrants (NCHECR, 2009).

Incarceration is not the only area where it is possible to see the way that illegality and criminalisation acts as a form of structural violence against people with a history of injecting drug use. As evidenced in the previous section, the illegality associated with injecting drug use also leads to high levels of stigma and discrimination and a strong moral abhorrence against people with a history of injecting drug use. While more research is needed to better understand the nexus between illegality, criminalisation, stigma, discrimination and moral attitudes, it is clear that poor attitudes towards people with a history of injecting drug use are creating very real barriers to access in relation to critical health and social services (ADBNSW, 2001). It is also clear from AIVL's recently commissioned market research into attitudes towards people who inject drugs that the current drug control laws directly contribute to the way in which illicit drug use is perceived as 'immoral' and effectively gives the 'green light' to poor treatment, social exclusion and discrimination against people who engage in this behaviour (Parr & Bullen, 2010).

Social theory describes the way in which acts associated with structural violence are legitimised and made acceptable in society, as 'cultural violence'. According to Galtung, cultural violence can make structural violence against a particular group feel right and acceptable by changing the 'moral colour' of an act often through ideology (Galtung, 1990). This process of legitimising structural violence through cultural violence is very apparent in relation to people with a history of injecting drug use particularly people who are actively using and people in pharmacotherapy treatment. Systems and institutions in society such as the current drug control laws routinely reinforce the 'acceptability' of stigmatising and discriminating against people with a history of injecting drug use and over time a pattern of cultural violence emerges.

There are 'layers' of impact associated with the criminalisation of people who use/inject illicit drugs which, when combined with other social factors such

as poverty, homelessness, lack of employment and/or education, incarceration, etc, can create extreme levels of disadvantage, social exclusion and health inequities. Creating laws that deem certain substances illegal leads to a damaging process of criminalisation that:

- Automatically creates a 'criminal class' of people – those who use or have used illicit drugs;
- Creates and re-enforces the regulation and control of those substances by the 'black market';
- Artificially inflates the cost of those substances so that people are forced to take greater and greater risks to get the money to buy them;
- Can lead to people who would otherwise have not had any contact with the criminal justice system committing a host of 'drug-related' offences often out of desperation;
- Makes people vulnerable to police attention and discretionary powers;
- Drives people away from family, community, information, services and support;
- Removes choice – in all aspects of life including health;
- Forces people to withhold or change information due to fear of the consequences of being honest;
- Drives people to take greater risk with injecting practices making them more vulnerable to BBVs;
- Leaves people vulnerable to sensationalist, inaccurate and invasive media reporting;
- Increases the likelihood of having children removed on the grounds of drug use alone;
- Results in people being unable to get or keep employment due to past criminal record or inflexible drug treatment programs;
- Leads to poverty and social exclusion;
- Results in people being removed from housing for being found to be on a pharmacotherapy program;
- Allows poor, inequitable and inhumane treatment to go unnoticed and unreported due to fear and/or because people see themselves as 'deserving' such treatment; and
- Results in people handing over their power, their rights and their dignity in exchange for access to basic services.

Due to illegality and the process of criminalisation people with a history of injecting drug use are an extremely vulnerable and marginalised group within our community. Currently there are no legislative protections to prevent poor treatment or discrimination against a person on the basis of presumed or actual, current or past injecting drug use. While there are some legal protections under anti-discrimination and disability law to protect people with hepatitis C, it is often near impossible for people to prove that the poor treatment was on the grounds of hepatitis C rather than presumed or actual illicit drug use. Even if this was possible, the process of criminalisation outlined above means that people with a history of injecting drug use are extremely unlikely to lodge a formal report or complaint due to fear of the consequences (Watchirs, 2010).

Being reluctant to assert one's rights or to even view oneself as having a right to be treated with basic dignity and respect has been labelled by social theorists as a process of 'symbolic violence' (Treloar, 2010). This process is described as the often unconscious internalisation and incorporation of 'structural and cultural violence' which in turn further legitimises those dominant actions (Bordieu, 1991). Through the imposition of certain ways of viewing and thinking about particular groups in society the dominant and the dominated come to accept the social order as 'right'. Society's disapproval of illicit drug use (which is expressed in both spoken and unspoken ways) acts in a coercive manner on people who use illicit drugs and results in them being complicit in their own subordination. It is this process that leads people with a history of injecting drug use to believe they don't deserve better treatment or at least do deserve the poor treatment that they so often receive at the hands of the system (Treloar, 2010). It is also this process that leads the general public to almost unconsciously accepting that discrimination against people with a history of injecting drug use is 'right' and as a community we should persist with actions despite the harm they might cause to individuals who use/have used illicit drugs (Parkin, 2009).

It is symbolic violence that underpins the extreme levels of shame experienced by people with a history of injecting drug use and their subsequent willingness to routinely submit to poor treatment and to empathise with those who have power over them. Bordieu labels this as a process of "misrecognition" whereby people with a history of injecting drug use come to see the discriminatory actions of those who have power over them not as the products of structural inequities but rather as reasonable responses to their individual failings and immoral behaviour (Bordieu, 1991). The impact of symbolic violence can also be seen in the actions of people with a history of injecting drug use as they attempt to negotiate the system and gain access to the

health services they need. The act of attempting to 'look like everyone else' and specifically, 'not look like a typical junkie' is in direct response to the ongoing impact of symbolic violence.

Treloar describes this process as "image management" and attempting to "pass into society" whereby people with a history of injecting drug use 'manage' their image (by the way they dress, talk, live, etc) so as to not appear to be a stereotypical drug user and in doing so gain access to what they need or simply to avoid poor treatment (Treloar, 2010). Unfortunately however, this process of attempting to "pass in" does not always result in people gaining access to services or fair treatment. The culture of fear, shame and distrust that surrounds almost every engagement that people with a history of injecting drug use have with the health system means that being discovered as 'managing one's image' can be perceived as simply providing further evidence of the inherent dishonesty of IDU. In many ways, for people with a history of injecting drug use it is quite simply a matter of 'damned if you do, damned if you don't.'

AIVL believes the illegality and criminalisation associated with injecting drug use is causing unacceptable levels of harm among people with a history of injecting drug use and is acting to create systemic barriers to health equity for this group in the community. For this reason AIVL believes there is an urgent need to commence a process of legislative and policy reform that reviews our entire approach to illicit drugs (and the attitudes that our current approach engenders) in order to improve access and service delivery for people with chronic hepatitis C.

b. Addressing Systemic Barriers to Access and Clinical Service Delivery for Hepatitis C:

AIVL is not naive about the complexity, scope and long term nature of the systemic reform we are proposing. We are also aware of the likely resistance we will encounter in advocating this position. The increasing evidence of the harms caused by the current approach to illicit drugs however means we simply could not produce a document on barriers to access and service delivery in relation to chronic hepatitis C without addressing this fundamental issue. We also believe it is unacceptable to continue to dismiss the need for reform as too difficult, too politically sensitive, unrealistic, etc. To do so literally means that as public health advocates and service providers we are saying that addressing the real barriers to access and service delivery for people with chronic hepatitis C is too difficult, too politically sensitive, unrealistic, etc. Furthermore, it says that the

health system will simply need to carry the cost of the increasing number of people with advanced liver disease and associated comorbidities because we seem unable or unwilling to address the fundamental structural and cultural factors that are driving the health inequities among people with chronic hepatitis C and a history of injecting drug use.

Claims that systemic reform to our current approach to illicit drugs is simply too difficult and would not be supported by the general community or politically are challenged by the recent policy announcement of the NSW Opposition Party. Shadow Attorney General Greg Smith announced that should they be elected, a NSW Coalition Government intended to undertake a process of reform that would lead to a significant reduction in the numbers of people in NSW prisons. In particular, he said they would target people with mental health issues and seek to reduce sentences for a “range of less serious offences” including minor drug offences, minor assaults and theft and fraud, etc (SMH, 27 July 2010).

While this approach has come under critique largely due to Mr Smith’s strongly held ‘zero tolerance’ position on other ‘minor’ offences such as public graffiti in the past, it is still interesting to note the rationale behind this shift in public policy. Part of the apparent reasoning is associated with an attempt to prevent the upcoming election descending into a ‘law and order auction’ on who can crack down hardest on crime. Mr Smith is also quoted as saying “the Coalition had come around to a more moderate stance on sentences for less serious crimes because the current attitude is costing us all too much” (SMH, 27 July 2010). We acknowledge this is only one jurisdiction, but it is the largest jurisdiction in terms of general and prison populations and when taken together with the priority actions identified in the national hepatitis C and HIV strategies, could be signalling the first signs of willingness at a political level to gradually move to more evidence-based and cost-effective approaches to issues such as illicit drug use.

AIVL believes reforming the current legal and policy approach to illicit drugs and thereby reducing the stigma and discrimination against those with a history of injecting drug use, requires a strategic, pragmatic and dynamic approach. In particular we believe the work of harmonising the current drug control laws with public health approaches should involve an iterative process of identifying the legislative and policy levers that may be more amenable to reform, assessing the impact of those reforms and then planning the subsequent ‘layers’ or ‘stages’ of reform. These subsequent stages will need to be part of an ongoing process of assessment, identification and change. Too often such reform is characterised as an ‘all or nothing’ approach.

Unfortunately this has been used to all but remove the chance of a strategic and pragmatic approach to reviewing the true impact of our current approach to illicit drugs on health of Australian citizens and ensuring public health outcomes are always the priority.

International evidence also supports the need to address the health inequities among people with chronic hepatitis C through a range of targeted and strategic measures that integrate and acknowledge the complex connections between illegality, social exclusion and hepatitis C. An article by Joanne Neale in the *International Journal of Drug Policy* critically examines the concept of social exclusion as a way of understanding the needs of marginalised injecting drug users who are living with hepatitis C infection. She argues that while efforts to tackle broader social problems may be indirectly assisting vulnerable drug users, more “joined-up” strategies and targeted measures are needed including tackling negative community and professional attitudes and discriminatory practices, more integrated service provision, professional training and the involvement of people who inject drugs with hepatitis C into policy reform and practice debates (Neale, 2008).

It is not possible in a document of this kind to comprehensively explore the process of reform that needs to occur or provide any degree of detail on what that process might look like or could achieve. It is possible however to identify issues of significance and map some of the key components or goals of the reform process with the aim of encouraging further discussion and action on this issue. As outlined above, any process of reform will necessarily take time as it will involve building a level of community consensus on the need for and benefits of change. Such community support is not built overnight and in itself will require a gradual process of staged change, acceptance and further reform. This will be extremely important in relation to gaining lasting and meaningful change on an issue that is often emotionally and politically charged.

We do however have previous examples in the BBV area from which we can draw in this regard. In the early 1990’s the then Inter-Governmental Committee on AIDS (IGCA) Legal Working Party delivered a report with recommendations on the need for legislative and policy reform to support effective responses to HIV/AIDS in Australia. As noted in *The National Hepatitis C Strategy 2010-2013*, reform did occur in line with the IGCA LWP recommendations in relation to gay men and men who have sex with men (MSM) (DoHA, 2010). This reform process included, among other reforms, repeal of the laws making homosexuality illegal and introduced important legal protections in relation to HIV related stigma and discrimination (IGCA, 1992). The impact

of this reform process should not be under-estimated particularly in relation to changing community attitudes. It is an ongoing process of consensus building and reform and while there are still issues to be addressed in 2010, this reform process has significantly improved access and service delivery for HIV positive gay men/MSM in Australia.

Rather than viewing the reform process as something that is yet to begin, AIVL believes it is possible to argue that this process is already underway within the community. This is not just because of the statements from the NSW Opposition, the priorities in the national strategies or the above reforms among gay men/MSM, or even some of the limited progress in sex work law reform. But these issues taken together with the increased focus and investment in diversionary schemes highlight a shifting agenda. We do not believe these actions are sufficient but it does reflect an awareness of the need for change and demonstrates the capacity of both the system and the community to accept change. Learning from these other relevant reform processes, AIVL believes addressing systemic barriers to access and service delivery for people with chronic hepatitis C and a history of injecting drug use would need to include the following broad components:

i. Enshrining a human rights framework:

The Ottawa Charter emphasises that social justice and equity are fundamental prerequisites for health (WHO, 1986). In this context, AIVL believes our approach to addressing the health needs of people with chronic hepatitis C and a history of injecting drug use should be underpinned at a strategic level by the principles and practices of human rights. Taking a human rights approach to these issues would mean creating a supportive social, policy and legal environment where human rights are respected and protected, and 'the equitable right to health' is not just an ideal articulated in international conventions (ICESCR) but an outcome that is both achieved and measured. There are increasing calls for a human rights-based approach to addressing drug policy issues at the international level (Barrett, 2008). The centrality of a human rights approach to improving access and service delivery for people with chronic hepatitis C and history of injecting drug use is also specifically identified in *The National Hepatitis C Strategy 2010-2013* which states as one of its guiding principles the need to support the:

"... formulation and application of law and public policy that support and encourage healthy behaviours and respect for human

rights as this protects those who are vulnerable and marginalised, promotes confidence in the system and secures support for initiatives."(DoHA, 2010)

Three general human rights principles are seen as key to characterising 'the equitable right to health' namely non-discrimination, participation and accountability. The impact of stigma and discrimination on the health and lives of people with a history of injecting drug use is significant. Although research in this area is limited, available evidence shows that people who inject drugs and those on opioid pharmacotherapy treatments routinely identify stigma, discrimination and fear of poor treatment as among the main reasons they do not access primary health, harm reduction and other health and social services (Aitkin, 2002 and Treloar, 2004).

Recommendations for a human rights-based framework:

Embedding a human rights based approach to access and service delivery for people with chronic hepatitis C would include as a minimum:

- **ensuring privacy protections and confidentiality in service provision;**
- **facilitating access to high quality, non-judgmental, client-focused health services;**
- **eliminating punitive drug treatment approaches and expanding current drug treatment options including injectable pharmacotherapies;**
- **developing legislative mechanisms to ensure the systematic review of existing and new legislation and policies for consistency with human rights principles.**
- **protecting the health and rights of people with a history of injecting drug use particularly in the health, social welfare and criminal justice systems;**
- **encouraging and supporting people with a history of injecting drug use to assert their basic human rights and to lodge complaints against those who violate those rights;**
- **conducting education and empowerment work with people with a history of injecting drug use to challenge the discourses created through structural, cultural and symbolic violence;**

- **conducting anti-discrimination and human rights focused education campaigns targeting the general community, government departments and health and social services;**
- **empowering people with hepatitis C and a history of injecting drug use to undertake self-advocacy and provide peer-based education and support; and**
- **ensuring the Australian Government’s Social Inclusion Agenda incorporates strategies to tackle the origins and impact of social exclusion on the health and wellbeing of people with a history of injecting drug use.**

A human rights approach would also ensure that people with a history of injecting drug use have unimpeded access to human rights agencies that can provide redress where violations occur. Such agencies could also provide educational and research measures to assist in recognising and reinforcing rights and responsibilities, measuring compliance and changing discriminatory and negative attitudes. A human rights approach enables the full participation of vulnerable people in the responses to issues that affect them and in society in general, empowering a community response which is fundamental to a true partnership. It also requires laws and policies that create and support health and wellbeing.

ii. Harmonising drug control laws and policies with public health approaches:

There is an urgent need to review our current drug laws and the unacceptable negative impacts they are having on drug users, their families and the community as a whole. In order to reform our current approach to illicit drugs and harmonise this approach with public health outcomes there are three strategies that this paper will consider:

1. **Diversions schemes;**
2. **Decriminalisation; and**
3. **Legalisation and regulatory frameworks.**

Generally these strategies are presented as separate and distinct options – almost as ‘alternative’ approaches. Rather than choosing one approach over another, AIVL believes it is far more useful to think about how diversion, decriminalisation and regulatory frameworks can work together across time as a progressive model of reform. Australia’s application of diversion is already well progressed however there are clear limitations to what diversionary schemes can achieve in relation to removing

criminalisation and illegality. For this reason, Australia needs to commence the process of decriminalisation as a strategy to reduce stigma and discrimination and to gradually build community support for more substantial and systemic reforms. These reforms would include the development of a new legal framework for regulating the use and availability of substances that are currently illicit. To support further discussion of how this gradual process of harmonising drug control laws with public health outcomes might work in practice, it is necessary to briefly outline the current context and explore some of the pros and cons associated with each of the strategies.

1. Diversions schemes:

The COAG Illicit Drug Diversion Initiative (IDDI) was announced in 1999/2000 and since that time there has been a significant expansion of both the number and types of diversionary schemes at the jurisdictional level (Hughes and Ritter, 2008). The main aims of the IDDI have developed over time as the program has been expanded to include court-based diversion as well as police diversionary schemes. To reflect this broader scope, the current aims of the IDDI are to 1) give people an incentive to address their drug use before incurring a criminal record, 2) to increase the number of illicit drug users diverted into drug education, assessment and treatment and 3) to reduce the number of people being incarcerated for use and possession of small quantities of illicit drugs (AIHW, 2008). The IDDI and other existing processes currently allow for a range of diversionary opportunities as the individual has contact with the criminal justice system including at the:

- i. **Pre-arrest stage** (generally referred to as police diversion) and can include fines, warnings, cautions, compulsory education, assessment, referral and treatment;
- ii. **Pre-trial stage** when charges have been laid but the issue has not yet been heard by a court and can include conditions of bail, conferencing and court discretion;
- iii. **Pre-sentencing stage** when sentencing is delayed while assessment and treatment is sought;
- iv. **Post-sentencing stage** which is part of sentencing such as drug courts, suspended sentences, circle sentencing, etc; and
- v. **Pre-release stage** such as being paroled before being released from a custodial sentence (Spooner, 2001).

The introduction of the IDDI in addition to existing diversionary options is a step in the right direction and an important aspect of gaining community consensus

for more substantial reform. There have now been numerous evaluations conducted of both the IDDI and specific jurisdictional programs which have found a range of positive outcomes from diversionary programs including reductions in drug use and criminal behaviour and improvements in physical and mental health and relationships with others (HOI, 2002, Bull, 2003, Hughes and Ritter, 2008).

Questions have been raised about the evaluations of diversion programs however largely due to methodological concerns relating to the difficulties of evaluating pilot programs with small sample sizes and short follow-up periods, over-estimating the size of effects due to control groups being poorly matched with the main sample and the use of varying methods to measure success and failure (Hughes and Ritter, 2008). AIVL has also noted, that examples used to evidence reductions in drug use and crime are predominantly drawn from cohorts of cannabis users. In this regard, other than data showing the cost-effectiveness of diverting people from the criminal justice system into drug treatment, there is a lack of evidence to show the impact of diversion on injecting drug use and related criminal activity.

There have also been criticisms of diversion as an approach due to its potential to be seen as 'net-widening' (Roberts and Indermaur, 2006) particularly in relation to increasing police discretionary powers, tightening bail conditions and requiring offenders to plead guilty to have access to the drug court process. Concerns have also been raised about the ethics, effectiveness and evidence-base to support the use of compulsory education, assessment and treatment in diversion particularly given that the degree of coercion increases as the levels of reoffending and problems associated with drug use increase (Spooner, 2001). While programs within the IDDI have evaluated well in relation to the quality of the relationships and communication between the criminal justice system and AOD services (AIHW, 2008), questions have also been raised about the way that diversion effectively turns the AOD sector and health workers into arms of the criminal justice system and vice versa (AIVL, 2001).

The exclusion of people with specific types of offences from certain court based diversion initiatives has also been questioned for the way that they can disproportionately disadvantage particular groups of people including Indigenous drug users. While some Indigenous specific measures have been developed to attempt to address this problem, the absence of culturally appropriate AOD services in rural and regional Australia is seen as a fundamental obstacle to addressing this issue effectively (AIHW, 2008). AIVL believes this

example also highlights the limitations of diversion in relation to effectively addressing the complex interplay between issues such as racism, criminalisation and illicit drug use.

Differences in the priorities and emphasis between the various jurisdictions has also meant a high degree of variability in the types of programs available which has led to gaps in services and poor access to diversion for some drug users (Hughes and Ritter, 2008). There are also more general concerns about the ability of offenders to meet the eligibility criteria and strict requirements of many diversionary schemes effectively meaning that some of the most marginalised people with a history of injecting drug use end up with criminal records and serving custodial sentences despite the availability of diversion within the system.

AIVL believes in the context of this paper, it is also important to assess the objectives and outcomes of diversionary measures in their broadest sense against the goal of addressing the fundamental social and structural determinants of health for people with a history of injecting drug use. As identified above, there is a weight of evidence demonstrating the negative impact of illegality and criminalisation on the health of people with a history of injecting drug use. While two of the main stated objectives of the IDDI are to prevent people incurring a criminal record and reducing incarceration rates for the use and possession of small quantities of illicit drugs, neither of these objectives were able to be effectively assessed in the evaluation of the IDDI due to a lack of quantitative and qualitative evidence from existing reporting mechanisms (AIHW, 2008). Further it is important to reflect on the reasons why COAG agreed to the IDDI which was to "make a new investment in combating drugs by combining strong national action against drug traffickers with early intervention strategies to prevent a new generation of drug users emerging in Australia" (MCDS 1999).

These dual goals of 'early intervention and prevention' and 'increasing the criminal sanctions against those who sell or supply illicit drugs' are focused on the prevention of illicit drug use per se rather than on reducing stigma, discrimination and criminalisation against those who use illicit drugs. While there are for practical purposes some 'decriminalising' effects of cannabis cautioning schemes if the caution is fully expiated, this is not the intended purpose of such schemes. Further, cannabis cautioning or even the totality of diversionary measures will never be able to reduce prison populations to the extent required to have a measurable impact on criminalisation and therefore the health of people with a history of injecting drug use.

While the opportunities for diversion at key junctures in the criminal justice process can be important for those who can access it and meet its requirements, diversion is not a new approach. Diversion, both through the IDDI and police discretion has been a mainstream practice within the criminal justice system for decades (Hughes and Ritter, 2008). The IDDI has allowed for the formalisation and therefore expansion of the use of diversion in a more systematic way and in this regard represents an important ongoing process of reform. The focus of diversion as it is practiced within the Australian criminal justice setting however is predominantly 'therapeutic' – that is aimed at diverting offenders into drug treatment and education rather than diverting them out of the criminal justice system (Hughes and Ritter, 2008). AIVL therefore believes additional measures are required to remove the impact of illegality and criminalisation on people with a history of injecting drug use.

2. Decriminalisation:

One possible solution to the current 'disharmony' between the current drug laws and public health approaches is to decriminalise (in whole or part) those substances currently associated with criminal sanctions. This does not result in these substances being legalised but it does remove the relevant offences from the criminal statutes and arguably some of the health and social problems outlined in this paper. Reports from countries such as Portugal who decriminalised possession of small amounts of previously illicit drugs for personal use (including heroin and cocaine) in 2001 have found that this has resulted in significant reductions in drug-related public health problems (Hughes and Stevens, 2007). To affect this change, Portugal introduced a new law that decriminalised the use, possession and acquisition of all illicit substances for personal use with 'personal use' being defined as 10 days supply.

These changes have not legalised the possession of illicit substances in Portugal but instead moved to a system of administrative sanctions rather than prosecution and criminal penalties. Growing, dealing or trafficking in illicit substances remain criminal offences. The policy decision to shift towards decriminalisation came about through the development of the equivalent of the National Drug Strategy in 1998/99. In addition to removing penal sanctions, the Portuguese have also introduced a system of Commissions for the Dissuasion of Drug Addiction (CDTs) which are made up of small panels of medical professionals, social workers and legal advisers. Police refer drug users to appear before the CDTs within 72 hours and the CDTs then choose between a range of administrative sanctions such as community service

orders, fines, removal of professional licences, bans on attending certain areas, etc. Dependent drug users are referred for treatment and cannot be subject to fines. In line with the stated aims of diversionary schemes in Australia, the main aim of decriminalisation in Portugal is to discourage new drug users and encourage dependent drug users to enter treatment (Hughes and Stevens, 2007).

Evaluation of the available data found that the impact of decriminalisation in Portugal has included decreases in heroin use, increases in drug treatment uptake and associated decreases in drug related deaths and levels of HIV and hepatitis C infections. It has also found that decriminalisation has directly led to increases in the scale of treatment and prevention activities in Portugal (Hughes and Stevens, 2007). Although there is limited data available on the outcomes from decriminalisation due to its extremely limited application, it is possible that removing offences from the criminal statutes would have a range of flow on effects such as changing attitudes to people with a history of injecting drug use because people will not be automatically seen as "criminals". In turn, this is likely to impact on the way that people see themselves, their rights and their health – indicators that are broadly suggested in the Portuguese experience particularly in terms of treatment uptake and BBV prevention. There are also the practical implications of not having criminal records interfering with people's ability to get work or keep housing and the impact of reducing levels of imprisonment on the health consequences that are currently associated with incarceration.

While Hughes and Stevens highlight that drug use patterns and associated health problems can operate independently from laws and policies, they conclude that although decriminalisation may have contributed to overall increases in drug use (largely associated with increases in cannabis use), it has at the same time led to reductions in drug-related public health problems (Hughes and Stevens, 2007). This is important because it focuses us back on the aim of any potential process of legislative and policy reform. It is worth restating at this point that *The National Hepatitis C Strategy 2010-2013* has identified the need to harmonise current drug control laws with public health approaches with the aim of addressing legal barriers to evidence-based BBV prevention strategies (DoHA, 2010). In this context, the aim of reform would not be to reduce illicit drug use per se (although this would not be discounted as heroin use has decreased under the Portuguese approach) but rather to measure success against the impact of reforms on drug-related public health problems. If this approach was taken, the Portuguese experience indicates that decriminalising personal use and acquisition of illicit

substances could have a positive and measurable impact on BBV rates and on people's willingness of come forward to access health services.

One of the unintended consequences of the decriminalisation process in Portugal has been an apparent increase in the use of certain recreational substances (most notably cannabis) due to a perceived increase in community tolerance (Hughes and Stevens, 2007). Although this could be perceived as a negative outcome, AIVL believes it is important to review the overall impact of decriminalisation in Portugal which in cost-effectiveness and public health outcomes alone could be argued to off-set this increase in recreational use. It is also important because 'increased community tolerance' could also indicate that decriminalisation may contribute in reductions in social isolation, stigma and discrimination for these reasons may also be an important and progressive step in addressing the social and structural determinants of health for IDU. When taken together with the decrease in incarceration rates and the subsequent savings to the system of people accessing treatment rather than being sentenced to a prison term, there is clear evidence to support the overall effectiveness and success of decriminalisation in Portugal (Hughes and Stevens, 2007).

The popular support for the process of decriminalisation that Portugal has undertaken is highlighted in the following quote from a recent report from constitutional lawyer Glen Greenwald for the CATO Institute which states:

"Notably, decriminalization has become increasingly popular in Portugal since 2001. Except for some far-right politicians, very few domestic political factions are agitating for a repeal of the 2001 law. And while there is a widespread perception that bureaucratic changes need to be made to Portugal's decriminalization framework to make it more efficient and effective, there is no real debate about whether drugs should once again be criminalized. More significantly, none of the nightmare scenarios touted by pre-enactment decriminalization opponents — from rampant increases in drug usage among the young to the transformation of Lisbon into a haven for "drug tourists" — has occurred."(Greenwald, 2009)

The limitation of decriminalisation however is that on its own, decriminalisation will not reorganise the way that current illicit substances are produced, acquired, bought/sold, etc, through the black market. Given that the cost of

illicit substances are directly associated with the financial hardship experienced by IDU, addressing the illicit market which underpins injecting drug use is a necessary part of any strategy to address IDU health and health inequities. This is supported in the data from the Portuguese experience which shows that decriminalisation in that context had no discernable impact on drug related crime (Hughes and Stevens, 2007). AIVL would posit that this is due to the fact that despite the lack of criminal sanctions for personal use, people are still forced to engage with the illicit drug market to purchase substances. With the cost of illicit drugs driving much of the harm experienced by people with a history of injecting drug use, this raises a significant question mark over whether decriminalisation alone would be sufficient to address the fundamental factors that create poor health among IDU.

3. Legalisation and Regulatory Frameworks:

Given the limitations of decriminalisation, AIVL advocates that an entirely new system of regulation or controlled distribution for substances that are currently classified as illicit should be introduced to replace the current prohibitionist approach. Despite a general reluctance within government to discuss alternatives to the current approaches to illicit drugs, AIVL believes there is evidence of community support for a more progressive and compassionate approach to these issues (Matthew-Simmons, 2008). The need for reform is already firmly on the international agenda with Transform Drug Policy Foundation in the UK recently publishing a monograph outlining practical strategies for reforming the current approach to illicit drugs titled: *After the War on Drugs: Blueprint for Regulation*. This monograph aims to "demonstrate that moving to the legal regulation of drugs is not an unthinkable, politically impossible step in the dark, but a sensible, pragmatic approach to control drug production, supply and use" (TDPF, 2009). It follows increasing public discussions in many countries in Europe, Asia and South, Central and North America on the need to end the war on drugs in favour of a more pragmatic and humane approach.

There are five main approaches to regulating currently illicit substances that have been canvassed in the international literature and are covered in some detail in *After the War on Drugs: Blueprint for Regulation*. While it is not possible or necessary to comprehensively outline these approaches here, it is worth providing a brief summary to encourage further consideration of these models in the Australian context. The five main regulatory models are:

- Prescription-based with pharmacy dispensing;
- Pharmacy-based sales;
- Licensed sales;
- Licensed premises; and
- Unlicensed sales (TDPF, 2009).

It is important to highlight that while these models are discussed in a theoretical context in relation to regulatory models for widescale drug law reform, variants of these models are in operation in numerous countries throughout the world supporting the legal distribution of medical, quasi-medical and non-medical psychoactive drugs (TDPF, 2009). Further, despite being broken into five distinct models they can be broadly summarised into two main approaches with differing levels of government regulation and control - one with an emphasis on the 'medical model' and the other on the 'free market/licensing approach' with some cross-over between pharmacy-sales and other non-medical licensed sales models.

“Medical Model” – this basically covers the prescription and pharmacy sales models outlined above and is based on the government controlling and regulating supply through existing Pharmaceutical Benefits Scheme or other similar scheduling process and associated legislation, registration and enforcement bodies. Substances for personal use would be provided through community pharmacy or clinic environments similar to the availability and management of opioid pharmacotherapies and heroin prescription in those countries where they are available.

Given the evidence supporting the positive benefits associated with treatment options such as heroin prescription, such an approach would allow for an increase in the range of treatment options available in Australia to bring our treatment sector into line with world's best practice. This would include legislative and regulatory reforms to allow for currently illicit substances such as heroin, amphetamines and cocaine to be provided on prescription. This is supported by studies from the Swiss, Canadian and UK trials of injectable heroin prescription. All of these studies have found positive results in relation to improved social functioning, psychological health and reduced criminality by shifting illicit heroin use into the health system through a legally sanctioned program that legalises heroin acquired and used in that context (Lintzeris, 2009).

Despite the evidence supporting the effectiveness of the prescription/pharmacy-based model for regulating access to currently illicit substances such as heroin, this option has been criticised by users for failing to

shift away from the current approach of treating illicit drug use as a 'pathology requiring treatment'. This is supported by the fact that the prescription model is really only suitable for regulating dependent drug use which would not provide a functioning system for the majority of illicit drug use which is not dependent. Questions have also been raised about whether this model could inadvertently support the continuation of an illicit drug market for those who do not wish to engage in the highly regulated and restrictive medical approach.

Supporters of this option argue that this approach would remove the 'unknowns' from dependent illicit drug use particularly in relation to purity and quality and would regulate the price so that people could live functional and healthy lives without the need to commit offences to support their use. As part of addressing some of the perceived weaknesses of the model the pharmacy sales based models include the capacity for both prescription and over-counter sales for 'low-risk' substances and also include the capacity for a new class of 'non-medical' pharmacists which it is argued could provide a better model for non-dependent or occasional drug use (TDPF, 2009).

“Free Market Licensing Approach” – this involves government regulation through a free market mechanism similar to best practice approaches the availability and management of alcohol and tobacco with licensing and controls through legislation and policy. Models under this approach include both sale and consumption of substances. Controls relating to the vendor, supply outlet, product and purchaser would all be covered through legislation and enforcement mechanisms tailored to local needs and priorities. As with the pharmacy model, license holders may be required to undergo training to offer harm reduction and health information and support.

Licensed premises may combine elements of current licenced premises for alcohol sales, cannabis coffee shops, gambling and sex work premises with pharmacy-based models to ensure a safe and supportive environment. This approach could also include little or no licensing for certain low-risk substances other than standard product information and labelling and would largely be freely available or subject to localised restrictions or voluntary codes.

Many of the concerns raised about this option are similar to current concerns in relation to alcohol and tobacco regulation and availability such as preventing access by minors, the ethics of overt advertising and promotion, promoting responsible use and the impact of health, social and lifestyle factors associated with use, etc. Supporters of this option argue it is the only way to remove the stigma and discrimination associated with

illicit drug use and that it would have all the benefits of the 'medical model' without the pathologisation of drug use/users. Advocates also argue that as each substance has different qualities, effects and health and psychological impacts there is little to be gained from making direct comparisons with current legal substances such as alcohol and tobacco.

Both of the above options (to greater and lesser extents) address the issues of illegality and associated criminalisation by making currently illicit substances legally available within the particular regulatory system. In this regard, these options aim to provide all the benefits associated with decriminalisation while also removing the negative consequences associated with substances being illegal. Both options generally also include some form of government subsidy (in the first option) or tax/excise (in the case of the open market option) to allow for the continued provision and/or expansion of quality AOD treatment and health services, information, education and support, etc. It should be highlighted however that research has shown in relation to heroin prescription, that the detail of the model and approach does matter to consumers. It is not uncommon for people to opt out of such heroin prescription programs due to the overly medicalised and restrictive approach to availability with people choosing instead to remain in the illicit market with all of its associated vulnerabilities (O'Mara, 2003).

It is a far more difficult task to assess the potential effectiveness of regulatory models to legalise currently illicit substances as, unlike diversion and even decriminalisation, we are largely still in the space of contemplating theoretical models. It is precisely this lack of concrete models and options which led to the development of TDPF's *Blueprint for Regulation*. There is understandably a degree of reluctance, even fear in contemplating fundamental reform of our current approach to illicit drugs. The reform of the health system in Australia presents us with a unique opportunity to progress the issue of legislative and regulatory reform in relation to illicit drugs. We have already commenced this process with the investment in diversion. We now need to take the opportunity to continue the transformation of our approach to addressing the health issues raised by illicit drug use. We can opt to continue to invest in strategies that are primarily focused on trying to prevent illicit and injecting drug use, but evidence does not support either the effectiveness or cost-effectiveness of such an approach.

Recommendations for harmonising drug control laws with public health approaches:

Ultimately, regardless of ideology and personal views on the availability and use of illicit substances, there are ethical, social and health imperatives driving the need to review our current approach. AIVL believes it is time

to ask: "What constitutes the harmonisation of drug control laws and public health approaches and how is this best achieved?" Further, these questions need to be considered in the context of the best interests of all Australians including people with chronic hepatitis C and a history of injecting drug use. As it currently stands the interests and needs of this group in the community is not being served by the current legislative and policy approach to illicit drugs. It is in the interests of the entire community to achieve 'harmony' before further harms are inflicted. AIVL believes this process should include a review of the health and social impact of current drug laws and policies with a view to replacing the current approach with a regulatory system of controlled supply that is focused on health and wellbeing rather than criminalisation. To ensure a comprehensive and progressive model of reform AIVL recommends:

- **Continuing the development and implementation of diversionary schemes including an increasing focus on:**
 - » Innovative strategies to divert people away from the criminal justice system and reduce reimprisonment rates rather than largely focusing on the opportunistic diversion of people into compulsory, abstinence-based drug treatment – this may include greater use of opioid pharmacotherapy in the community, voluntary community-based support and development programs, etc;
 - » Exploring justice reinvestment as a way to create alternatives to incarceration for highly marginalised people with a history of injecting drug use – that is using resources that are currently allocated to incarcerating people to be 'reinvested' in strategies to keep people with drug related offences out of prison;
 - » Addressing the barriers to accessing diversionary schemes - particularly for Indigenous IDU, people in regional and rural communities and those convicted of certain classes of offences including offences that are classified as violent and people with convictions for violent offences in the past.
- **Expanding the use of decriminalisation beyond simple cannabis offences to include:**
 - » Decriminalising the purchase and possession of small amounts of all currently illicit substances for personal use - up to 10 days supply assessed on individual levels of use and circumstances;

- » Developing a system of civil penalties for small-scale supply of all currently illicit substances when the supplier is a user of and/or dependent on the substance supplied.
- **Exploring the potential for replacing the current drug control laws with a new system of legal regulation including:**
 - » Undertake the necessary reform to expand pharmacotherapy treatment options to include the implementation of heroin prescription programs through the existing community prescriber and pharmacy dosing model utilised for methadone and buprenorphine – needs to take into account the models and the lessons learnt from heroin prescription trials and programs in other countries including the factors that ensure such programs are accessible and attractive to the client group;
 - » Commissioning research to provide the evidence base and ‘blueprint’ for a gradual process of legislative reform to result in a new regulatory system for the availability of all currently illicit substances;
 - » Undertake an independent audit of the ‘net harm’ caused by current drug control laws, policies and approaches – should include a specific focus on the net effect of law enforcement and interdiction on the health and wellbeing of people with a history of injecting drug use.

As stated at the outset of this section, the process to harmonise current drug control laws with public health outcomes will take time as it is critical that it is a genuine, progressive and comprehensive process. While this occurs, there are other initiatives that can also be undertaken and/or further developed to address some of the practical and environmental barriers to access and service delivery for people with chronic hepatitis C and a history of injecting drug use. While some of these ‘environmental’ measures are very important and will have positive practical effects for some people with chronic hepatitis C and a history of injecting drug use, they will not on their own transform the more fundamental structural barriers to access and service delivery for our community. It is a matter of making a genuine commitment to progressing systemic reform to address structural barriers to access while simultaneously creating service delivery models that, in the short term will improve access for some, but in the longer term should ‘join up’ with the systemic reform to create models of access and service delivery that work for the majority of those affected.

c. Addressing Environmental Barriers to Access and Clinical Services Delivery for Hepatitis C:

In addition to employing strategies to address the ‘systemic barriers’ identified in the previous section, there is also a need to understand and address a range of other barriers to existing hepatitis C service delivery that are best described as ‘environmental’ barriers. This will be done through a brief overview of the major types of existing services in hepatitis C primary prevention and secondary and tertiary care, identification of the main barriers to access and service delivery within these models and proposal of key recommendations for addressing barriers. This will be followed by a brief assessment of any other service gaps and support issues for people with chronic hepatitis C and a history of injecting drug use. In relation to hepatitis C treatment and management some additional ‘overarching’ environmental barriers will also be considered that are relevant to all service models or types. The recommendations from the above assessment will attempt take into account opportunities that may arise from the current process of reform in the Australian health system.

While we have made use of evaluations and research into the issues and barriers for people with chronic hepatitis C and a history of injecting drug use where available, the peer-based nature of AIVL and the shortage of formal work on some of the relevant issues has meant that we have also relied on anecdotal reports, personal testimonies provided for user magazines and resources and personal experiences noted in focus groups and peer support environments. AIVL believes this ‘anecdotal’ information constitutes an important source of evidence for increasing our understanding of the needs of a highly marginalised group in the community. In many instances this information has added depth to some of the more formal research findings. All of these communications are characterised in the text as “peer report”.

As outlined above, it is recommended that best practice approaches to meeting the needs of people with chronic hepatitis C need to be based within a primary health care framework. This will ensure comprehensive and integrated models of access and service delivery that are person-centred, focused on a continuum of care and can encompass multidisciplinary team approaches to complex and chronic conditions. The development of such service models can ensure access across prevention, diagnosis, treatment and management. While development and implementation of such comprehensive and integrated models of care are already

underway at the jurisdictional level, high ongoing rates of HCV and other BBV infections and extremely low levels of HCV treatment uptake indicate that multiple barriers to access and service delivery remain. These barriers are significantly impacting on our ability to effectively respond to hepatitis C. Understanding the specific environmental barriers experienced by people with a history of injecting drug, in context, is necessary if we mean to develop effective strategies to address them.

i. Hepatitis C Primary Prevention:

Given the profile of the HCV epidemic in Australia, our hepatitis C primary prevention services are mainly based around an extensive national network of needle and syringe programs (NSPs), pharmacy-based NSP, secondary NSP outlets (incl. hospitals and community health centres), outreach services and other outlets (incl. AMS). Peer-based NSPs run by drug user organisations make up some of the major primary and secondary outlets across the country. Vending machines are also gradually being added to the service mix to extend access to new injecting equipment. In addition to access to new injecting equipment, there are a range of hepatitis C and other BBV prevention education services and programs operated by peer-based drug user organisations and other community based services. Harm reduction-based AOD services such as opioid pharmacotherapy programs can also provide access to hepatitis C and other BBV prevention education.

Too often models of access and service delivery for people with chronic hepatitis C infection focus only on disease treatment and management in tertiary care settings. Models of hepatitis C access and service delivery for people with a history of injecting drug use however, must include comprehensive and integrated approaches that include a focus on the prevention/care continuum. There are a range of reasons why access to effective primary prevention remains important for people with chronic hepatitis C infection including the risk of increased disease progression associated with HIV and/or hepatitis B co-infection (ASHM, 2009), the role of people with hepatitis C in preventing further transmissions and the potential for re-infection following successful hepatitis C antiviral treatment.

Ongoing access to hepatitis C primary prevention services such as NSP and peer education can also play an important role in maintaining and improving the general health of people with chronic hepatitis C through the prevention of other drug-related harms including abscesses, bacterial infections, endocarditis, etc. In addition to the above issues, primary prevention services (particularly peer-based services) can also be key

to increasing access and reducing barriers to secondary and tertiary care services (Aitkin, 2001). For example, a number of NSP and peer-based drug user organisations in Australia operate BBV & STI clinics which provide in-house BBV prevention, testing and referral to more specialist services.

Barriers to Primary Prevention Services:

The National Hepatitis C Strategy 2010-2013 has identified the need to expand access to new injecting equipment through NSPs and reduce reusing of injecting equipment as priority actions in hepatitis C prevention and education (DoHA, 2010). AIVL has recently released a comprehensive document on the legislative and policy barriers to NSP and new injecting equipment access. While it is not possible to detail all of the barriers to service access here, the major legal, policy and environmental barriers identified in the report include:

- Increasing restrictions on the amounts and types of injecting equipment available at NSPs – due to both legal and policy restrictions including restrictions on peer distribution;
- Lack of culturally appropriate services for Indigenous and CALD IDUs;
- Lack of access to injecting equipment in prisons;
- Limited hours of NSP operation and poor advertising of operating hours;
- Mandatory reporting – particularly for young people and women with children;
- Cost of transport/lack of transport to access services;
- Fines for carrying injecting equipment on public transport (not all jurisdictions);
- Fear of being identified as a drug user if seen entering/leaving an NSP including coming to police attention;
- Lack of privacy/confidentiality of service users in regional and rural areas with few services;
- Poor attitudes and discrimination from NSP staff – particularly secondary services;
- Surveillance by police, drug treatment services, family services, etc – real or perceived;
- Lack of awareness of NSP sites;
- General lack of amenities at NSPs – no parking, poor access to building, etc.

The National Hepatitis C Strategy also identifies the need to increase access to targeted hepatitis C education and health promotion and strengthen the skills of the hepatitis C prevention education workforce including IDU peer educators (DoHA, 2010). While increasing the availability of prevention education services and ensuring there is a well-trained and supported prevention workforce are both essential, there can be other reasons why people may not engage with hepatitis C prevention services. Research and evaluations have shown that people at risk of and with hepatitis C often have poor levels of knowledge in relation to hepatitis C prevention (Aitkin, 2001) despite seeing themselves as being well informed on the subject (AIVL, 2010).

High levels of complacency about the seriousness of hepatitis C infection, confusion about hepatitis C status and other competing health and social priorities have also been identified in research as factors contributing to a lack of engagement on hepatitis C prevention (ASHM, 2009). A lack of awareness of the potential implications of co-infection with HIV and/or HBV and being uninformed about the potential for re-infection following successful treatment can also be reasons for why people with chronic hepatitis C infection may not view themselves as needing to access primary prevention services.

The barriers to accessing hepatitis C primary prevention services within the AOD sector are quite specific. People with a recent history of injecting drug use have poor access to primary health care (Reid, 2000, McNally, 2004) and therefore unless people are on opioid pharmacotherapies it is unlikely that they will have regular contact the health care system. Research also shows that people with a history of injecting drug use are very reluctant to speak about their drug use with any health care workers they do access for fear of poor treatment and discrimination (Aitkin, 2002, Norman, 2008). People on opioid pharmacotherapies also report fear of disclosing current injecting drug use with their prescriber due to concerns about removal of 'privileges' such as take home doses (Peer report). These factors separately or together can therefore greatly reduce the likelihood of people with a history of injecting drug use accessing BBV prevention services in the AOD context.

Addressing Barriers to Hepatitis C Primary Prevention Services:

To address the barriers to hepatitis C primary prevention services for people with chronic hepatitis C and a history of injecting drug use AIVL recommends:

- **Improving access to primary health care services for people with a history of injecting drug use** – there are opportunities presented by

the current health system reforms particularly through the development of the primary health care organisations (PHCOs) and Medicare Locals (MLs) to increase access to primary health care for IDU. This should involve the development of culturally appropriate services, services for highly marginalised groups of drug users and better access to general primary health care for the broader population of people with a history of injecting drug use. New service models need to be developed that include multidisciplinary team approaches and peer education and support as core components of any model in the delivery of primary health care for people with a history of injecting drug use.

- **Increasing access to new injecting equipment through NSP particularly peer-based NSP** – there will be opportunities within the national health reform process to improve NSP service delivery. While it is not yet clear where NSP services will 'sit' within the new system, AIVL believes there are opportunities to expand access to NSP through purchasing arrangements at the state/territory level through the new LHNs and PHCO/MLs. Alternatively, if responsibility for NSP was shifted to the federal level through the new National Preventative Health Agency, AIVL believes this would require the development of key indicators to support increased resourcing and commitment for a national NSP infrastructure. The benefits of this approach is that it would secure a nationally consistent level of access and service delivery but achieving this would also require the agreement of a set national NSP standards. AIVL would be concerned that such standards would need to operate at 'best practice' not 'minimum' standards. Whether funding and policy responsibility for NSP remains at the state/territory level or shifts to the Commonwealth, there is now a wealth of evidence supporting the need for existing NSP services to be increased in capacity, number and scope. In particular AIVL would recommend the need to expand access to peer-based NSP services through the expansion of existing peer-based NSPs and through the establishment of new peer-based services. New arrangements under the health reform process will create the opportunity and resourcing for this to occur particularly by adding peer-based NSP to the service mix in the LHNs and MLs.
- **Review of legal, policy and structural barriers**

to NSP and injecting equipment access – each jurisdiction should undertake a full review of the relevant legislation, policies and regulations governing the operation of NSP (and other hepatitis C prevention services) to ensure barriers to access are removed. This would include an all of government approach to ensure that issues such as drug control and public health legislation, mandatory reporting, local council regulations, policing practices and environmental planning are all taken into consideration. These issues will also need to be considered in light of the above health system reforms.

- **Peer distribution of injecting equipment** – as part of the above review, priority should be given to undertaking the necessary reforms to allow peer distribution of injecting equipment. Further detail and specific recommendations on peer distribution of injecting equipment can be found in AIVL's recently published discussion paper *Legislative and Policy Barriers to NSP and Injecting Equipment Access* available on the AIVL website.
- **NSP in prisons** – once again, although this issue would also need to be considered as part of a comprehensive review of legal, policy and structural barriers to NSP access, the urgency of this reform measure in relation to public health and human rights warranted a stand-alone recommendation. Further detail on models and approaches and specific recommendations can be found in AIVL's NEP in Prisons discussion paper on the AIVL website. The need for jurisdictions to seek opportunities to trial NSP in prisons is also addressed in The National Hepatitis C Strategy 2010-2013.
- **Workforce training and support** – ongoing and mandatory training for all NSP staff in addressing stigma and discrimination and poor attitudes towards people with a history of injecting drug use should be a standard inclusion in all service delivery models.
- **Promotion and advertising of NSP services** – strategies need to be implemented to improve access to information about the locations, operating hours and services of NSPs and other BBV prevention services within the general community.
- **Increased IDU peer education** – improved access to peer-based prevention education in relation to hepatitis C to address myths and misinformation and increase awareness among people with chronic hepatitis C and a history of injecting drug use of the need to have ongoing access to well-targeted primary prevention services.

- **Hepatitis C Prevention in AOD Settings** – there is a need to provide access to up to date information on BBV prevention and related issues for people with chronic hepatitis C infection who are on opioid pharmacotherapies. Strategies need to be developed to provide access to this information without individuals being forced to disclose current injecting drug use. This could include printed and audio/visual information available in waiting areas, use of peer support workers, peer support groups, internet access points, availability of drug user magazines and resources, public information sessions and readily available referral information. Ultimately there needs to be policy change to remove the punitive aspects of opioid pharmacotherapy and other AOD treatment approaches. Over time, if people found they did not experience negative outcomes and punishment associated with discussing current injecting drug use in the AOD treatment context, then they may be more willing to access BBV prevention and harm reduction in this environment.

ii. Hepatitis C Testing and Diagnosis:

Australia has a National Hepatitis C Testing Policy that was first developed in 2003 and was reviewed and republished in 2007. The National Hepatitis C Testing Policy primarily functions as a technical document to benchmark best practice standards for testing and diagnosis for use by health professionals, government, the healthcare industry and people at risk of and with hepatitis C. The policy is guided by seven key principles that are meant to underpin all hepatitis C testing in Australia which are that:

- confidential, voluntary testing with informed consent and pre-test and post-test discussion is fundamental to Australia's response to hepatitis C;
- testing is of the highest possible standard;
- testing is of benefit to the person being tested;
- testing is accessible to all those at risk of HCV infection;
- testing is critical to understanding the epidemiology of HCV infection in the community;
- testing can be critical to interruption of transmission and can support harm minimisation; and
- testing to monitor people with hepatitis C before, during and after treatment is an integral part of their care (DoHA, 2007).

Currently HCV antibody testing is MBS rebatable and other quantitative and qualitative testing such as viral load, PCR and genotyping are also MBS rebatable under specific conditions. In addition to these diagnostic tools some states and territories also offer free deidentified testing such as testing without a Medicare card although this is very limited and usually only available to groups such as young people and Aboriginal IDU in the community health/primary health care context (ANCAHRD, 2003).

Despite the existence of the National Hepatitis C Testing Policy however, it is recognised in *The National Hepatitis C Strategy 2010-2013* that there has been a lack of implementation of the policy which has “created poor diagnostic practices, including inadequate access to pre- and post-test discussions at the time of diagnosis, and subsequent insufficient referral to clinical and support services” (DoHA, 2010). It is also recognised that there can be structural barriers to accessing testing and ongoing monitoring for people at risk of and with hepatitis C who have a history of injecting drug use.

Although this paper is focused on the needs of people already diagnosed with chronic infection there are a range of reasons why testing and diagnostic services remain relevant for this group. The importance of both initial assessment and ongoing monitoring for the health maintenance, treatment and care of people with chronic hepatitis C infection is well documented in the literature (Dore, 2009a, ASHM, 2009). In addition to diagnosis and opportunities for education and information provision, the quality of initial testing is extremely important. It can have a profound effect on not only a person's understanding of their condition and what options they may have in relation to treatment and management, but it can also have direct implications for how, indeed whether, they will engage with the health system in relation to their hepatitis C diagnosis in the future. This point is highlighted by Loveday in *Hepatitis C an Expanding Perspective*:

“A positive hepatitis C diagnosis, delivered in a negative, dismissive or judgemental manner or with incorrect information, can have a significant detrimental effect on a person's outlook with potential long-term consequences. On the other hand, a positive hepatitis C diagnosis, delivered in a supportive, informed and non-judgemental way, can provide a solid foundation on which the person receiving the diagnosis can take control and start their journey of living with a chronic health condition.” (Dore, 2009)

Other issues such as assumptions being made by clinicians about people's lives and risk practices, feeling ‘forced’ into testing and seeking to test people at inappropriate times can also affect how people will engage with the condition and their situation. Practical difficulties such as transport and getting to clinical and laboratory settings, costs associated with paying for GP and specialist consultations and certain diagnostic testing and the impact of poor vein care due to long term injecting drug use are some of the additional reasons why understanding the barriers to accessing testing and ongoing monitoring services for people with chronic hepatitis C is essential.

Barriers to Hepatitis C Testing & Diagnosis:

Research into barriers to testing is very limited but the available data on why people may not come forward for initial hepatitis C assessment and antibody testing can provide some useful insights into why once tested, people may not return to collect results, may not wish to discuss results in detail, may not consent to confirmatory testing if antibody positive and may not attend for ongoing monitoring of chronic hepatitis C infection, etc. Research into reasons for never being tested for hepatitis C suggest a combination of factors that can act alone or in concert including:

- A lack of awareness of their need for testing;
- Myths and misinformation about risk factors;
- A lack of an appropriate testing situation;
- Complacency about hepatitis C;
- Not prioritising hepatitis C;
- Fear of the result;
- Fear of disclosure and the likelihood of discrimination from the doctor (Aitkin, 2002).

In the alternative, the reasons participants in the same research gave for agreeing to be tested as part of the study were clustered under four linked areas of:

- Convenience and ease of the testing situation;
- Feeling comfortable and safe in the testing environment particularly because the testing was being done by a trained peer worker;
- Were uncomfortable disclosing their IDU status to their regular doctor or expected to be treated poorly in clinical settings; and
- Were motivated by a recent risky incident (Aitkin, 2002).

Direct links can be made between these themes and issues and the types of barriers to ongoing monitoring for people already diagnosed with chronic hepatitis C. For example, a lack of information and understanding about the need for confirmatory testing and the value of ongoing monitoring can result in people disengaging with the health system and developing dangerous levels of complacency about their need to be aware of disease progression, liver health and ongoing lifestyle factors. Despite the existence of the National Hepatitis C Testing Policy and associated testing algorithms (ANCAHRD, 2003) anecdotal reports suggest that too often people are testing HCV antibody positive only to be told that the likelihood of them being PCR positive is so high because they have a history of injecting drug use that confirmatory testing is not needed (Peer report). This lack of implementation of the national policy in relation to HCV RNA testing for people who have a positive hepatitis C antibody test is also noted in the *National Hepatitis C Strategy* (DoHA, 2010). These practices can result in people believing they have chronic hepatitis C infection when they may have cleared the virus and/or can lead to people being overly complacent about their condition. This is extremely important given that at least 30 percent of people clear HCV infection without treatment (Dore, 2009, Hellard, 2009).

Feeling safe and comfortable in the clinical setting in which testing and monitoring occurs is very important in relation to pharmacotherapy settings. Although there is research showing people on methadone programs are more likely to be considered hepatitis C treatment and therefore undergo the diagnostic work-up necessary for treatment access (Day, 2008), AIVL would question whether this is a result of people feeling more comfortable in the methadone treatment setting (as has been suggested) or whether other factors may be at work. For example, anecdotally it is very common for people on pharmacotherapy programs to talk about the lack of informed consent in relation to BBV testing in this context. Many pharmacotherapy consumers mention feeling 'forced' to undergo hepatitis C testing at the time of entering the program due to fear that they may not be accepted on the program or there would be delays to dosing if they refused. Although AIVL is not suggesting that compulsory testing is occurring in this context, there does need to be an awareness among healthcare providers of how testing can be perceived by people in highly vulnerable situations. There also needs to be a questioning of whether hepatitis C testing at the time of pharmacotherapy commencement can ever really involve full informed consent. As outlined above, is also important to consider how testing at a time and place viewed as inappropriate by the individual could impact on the way that person views and engages with their hepatitis C diagnosis in the future.

Feeling uncomfortable in the clinical setting particularly concerns about disclosing injecting drug use and the likelihood of resulting discrimination and/or actual experiences of poor treatment can act as major barriers to access and service delivery for people with a history of injecting drug use (Treloar, 2002). The high levels of stigma and discrimination experienced by people with hepatitis C and a history of injecting drug use in health care settings is now well documented (ADB NSW, 2001, Brener, 2007). While not all health care professionals engage in stigmatising and discriminatory behaviour towards people with a history of injecting drug use, it is believed that a combination of both expectation of poor treatment and actual experiences of same frequently have a negative impact on the development of non-judgmental, trusting relationships between physicians and their drug using patients (Sutton and Treloar, 2007).

Even where the relationship between the clinician and the patient is relatively good in relation to discussing hepatitis C and other health issues, there can still be high levels of concern about discussing anything that may lead to or require a disclosure of recent injecting drug use. This is particularly the case when people are on opioid pharmacotherapies and where their physician is also their pharmacotherapy prescriber or where there is a referral pathway between the hepatitis C specialist and their prescriber. People have often had poor experiences of being honest about injecting drug use with their prescribing doctor such as losing access to take home doses, increased monitoring such as urine testing, having restrictions placed on their access to other medications such as benzodiazepines and being referred back to far more restrictive 'low threshold' programs. People are also concerned that any disclosure of recent injecting drug use could also result in poorer access to pain management medications which is important particularly if they are contemplating hepatitis C treatment.

Concerns about identification of recent injecting drug use is not only limited to disclosure by the patient. As signs of recent injecting drug use can often be visible particularly for older users with vein problems in the form of puncture marks, bruising and scarring, perceptions and actual experience of how the treating physician will respond to such signs can be critical to patient decision making. In particular, people may make decisions about whether to present for important ongoing monitoring and testing for hepatitis C based on whether they have any visible signs of recent injecting. Depending on the level and frequency of injecting drug use, the person may become 'caught' in a ongoing cycle of fear about recent injecting being discovered, resulting in little or no ongoing monitoring of their hepatitis C or disease progression.

One of the other issues that cannot be under-estimated when it comes to barriers to testing and diagnosis for people with hepatitis C and a history of injecting drug use is the issue of poor vein care. Problems associated with scarred, collapsed and over-used veins from injecting drug use can act as the single biggest reason for not undergoing testing and diagnosis and one of the main reasons why people put off dealing with serious health issues for many years until late presentation. The inability of venapuncturists and laboratory technicians to access working veins for the purposes of hepatitis C diagnostic testing can be extremely traumatic particularly for people who have not injected for many years and for whom treatment is critical. It is not uncommon for people with a long history of injecting drug use to recount stories of very difficult experiences that do not result in the required sample even after exhausting all 'possibilities' in arms, hands, feet, etc. These adverse experiences frequently result in people avoiding both the testing itself and return visits to the physician who ordered tests as "no-one ever seems to quite believe that your veins can be that bad" (Peer report). This issue is acting as a significant deterrent to hepatitis C monitoring and treatment for some people and for this reason there is a need for the development of specialist skills and services to ensure this unnecessary barrier is removed.

A 2007 study, *Acceptability of Hepatitis C Virus Testing Methods Among Injecting Drug Users*, looked at various tests for hepatitis C and how they were received by people who inject drugs. The tests evaluated were venous blood, capillary blood and oral fluid. The researchers concluded that "oral fluid testing is an acceptable and preferred alternative for HCV testing among IDUs. However, concerns reported by participants in the study indicate that information and education regarding the nature and diagnostic value of oral fluid testing is necessary prior to its implementation". Individuals preferred the oral fluid test based on the fact that "the procedure was easy, pain free and non-invasive". Though some participants were concerned about issues such as accuracy of the test, "findings suggest that negative perceptions of the test are likely to be responsive to education campaigns" (White, 2008).

As outlined above, a number of factors affect the likelihood of people who inject drugs presenting for testing for hepatitis C infection. These include the reasons for being tested, barriers to being tested and the experience of undergoing testing (including vein problems and the setting in which the test is conducted). Day et al examined some of the factors that influence a person's decision to be tested for hepatitis C and found that:

- *Testing... links drug users... to a range of services and increases opportunities for health promotion, harm reduction and uptake of drug treatment;*
- *Counselling at the time of testing has been shown to reduce risk behaviours;*
- *Knowledge of one's serostatus has been shown to impact IDUs' injecting risk behaviour;*
- *...fear of a positive result and difficulty keeping appointments were identified as the main barriers to testing;*
- *One-quarter of the sample reported having previously been tested for HIV and HCV but not returning to get their results;*
- *...reasons for seeking testing in the past were preventing transmission to others... potential exposure to infection... and to obtain early treatment;*
- *Twenty-four percent of participants reported that they would prefer to take their own blood;*
- *Given the substantial knowledge and experience in venepuncture accumulated by some IDUs, providing for supervised self-collection of venous samples may promote more regular testing (Day, 2008).*

Research has demonstrated that cost can act as a major barrier to people with a history of injecting drug use accessing testing and ongoing monitoring for hepatitis C (Novick and Kreek, 2008). Although antibody and certain diagnostic testing is government subsidised in Australia, this is only the case for those who are Medicare eligible and then only certain amounts and types of testing/diagnostics are covered. Additional or specialist diagnostics such as ultra-sounds, scans, xrays, etc are not always covered and this is becoming more of an issue as people with a history of injecting drug use require access to more determinations, medications and medical services in relation to hepatitis C, ageing and complex comorbidities. This is before additional issues such as the cost of transport to allow people to get to appointments and testing services are taken into account for a group that experience high levels illicit drug-related poverty and generally live on very low incomes.

People with a history of injecting drug use can sometimes have difficult relationships and even conflicts with staff in medical services over non-payment of fees, missed appointments, etc which often results in them being unable (or feeling unable) to return for testing and/or results or cannot take up referrals for diagnostic testing

because they either cannot afford the tests or they can't go back for a follow-up appointment. These kinds of issues are becoming increasingly common in the general practice setting where practice policies require even those on low incomes with healthcare cards to pay a fee or penalty for missed appointments even if they would have been bulk-billed for the original appointment. These penalties often must be paid 'on-the-spot' and before an additional appointment can be scheduled. This can be a particular problem in smaller metropolitan and regional and rural areas where choice of health care provider is often restricted. These policy arrangements can create an environment where even though there is subsidised access to testing and diagnosis relating to hepatitis C, people are experiencing difficulties in relation to access and service delivery that are primarily driven by cost-related barriers.

The increasing costs associated with medical appointments is also a major factor for people with chronic hepatitis C and a history of injecting drug use who are employed. Although people are waged, their incomes are often quite low/limited and they are not eligible for a healthcare card and therefore must pay standard consultation fees to access general practice and other specialist and allied medical services. In this regard, although the diagnostic testing associated with the ongoing monitoring of hepatitis C or in relation to preparation for treatment is subsidised, working people often cannot afford the basic consultation fees to allow them to access care in the community or to gain a specialist referral. This is exacerbated for people who are on opioid pharmacotherapy through a community-based prescriber as they are already carrying the cost of routine consultations for their prescription renewal (AIHW, 2009). Under these circumstances, people are frequently very reluctant to discuss anything but the absolute necessity of renewing their pharmacotherapy prescription for fear of having to afford long consultation fees (Peer report). In this way, this issue acts as another factor militating against hepatitis C monitoring and treatment becoming a priority for this group.

People with chronic hepatitis C who are employed are not well represented in the data on people with a history of injecting drug use. For the most part, sampling is not designed to capture this group so they are absent from the data and therefore our understanding of their needs is too often research on hepatitis C treatment in pharmacotherapy settings is done in public pharmacotherapy clinics which automatically skews in favour of those who are not currently employed as this represents a majority of people on public programs (Rowe, 2008). The majority of people with hepatitis C and a history of injecting drug use who are working are paying for their pharmacotherapy treatment, all of the

associated medical appointments and are often wrongly assumed not to be current drug users and therefore able to afford health care to the same degree as other working people. This assumption however does not take sufficient account of the long term impact of dependent drug use on a person's economic circumstances and security or the fact that many working people on pharmacotherapies live week to week without the additional support of owning property, having savings or meeting criteria for credit cards – many of the ways that other working people managing unexpected or increasing health costs.

Numerous factors including income level, current drug use (or not), medical costs associated with managing multiple complex and chronic conditions can all impact on whether a person with hepatitis C and a history of injecting drug use can afford to access hepatitis C testing and diagnostics. There is a need to improve our understanding of the diverse range of people with hepatitis C and a history of injecting drug use and their varying needs and issues in relation to accessing health care. In this regard, the needs of this group are not dissimilar to other groups with complex and chronic conditions who often require maximum access to health services but are least able to afford them due to the ongoing impact of illness on their capacity to earn, retain employment, etc. Research undertaken by the Consumers Health Forum of Australia found that people with complex and chronic diseases face far greater health costs than the general population (CHFA, 1997). If we wish to encourage people with hepatitis C and a history of injecting drug use to engage more in the diagnostic testing required for ongoing monitoring and treatment for hepatitis C, then we must address the barriers that prevent access and service delivery in this area.

Addressing the Barriers to Hepatitis C Testing & Diagnosis:

To address the barriers to hepatitis C testing and diagnosis for people with chronic hepatitis C and a history of injecting drug use AIVL recommends:

- **Improving access to education and information on hepatitis C testing and diagnosis for people with a history of injecting drug use** – there needs to be improved peer-based and community education to increase understanding about the need for confirmatory testing and the value of ongoing monitoring for people who are found to be HCV antibody positive. Such education could also support a greater understanding among people with hepatitis C of the testing process including the importance of pre and post-test discussion, the right to informed consent, etc.

- **Ensuring the implementation of the National Hepatitis C Testing Policy** – AIVL recommends the need for a review and development of a strategic communications plan to support effective implementation of the best practice standards within the National Hepatitis C Testing Policy including confidentiality, test discussion, informed consent and quality referral and support. This work should be led by the national advisory structures of the Blood Borne Viruses & STIs Sub-Committee of APHDPC and the Ministerial Advisory Committee on BBVs & STIs or their equivalents. This process will also need to be undertaken in partnership with relevant professional bodies and organisations including the RACGP, ALA, GESA, ASHM, NRL, etc.
- **Workforce training and support to address attitudes and values towards injecting drug use/users** – support and resourcing for the development and implementation of a national ongoing workforce training project aimed at addressing stigma, discrimination and poor attitudes towards people with a history of injecting drug use among health professionals involved in hepatitis C testing and diagnosis. The training would be designed to increase understanding among health professionals of the issues and needs of people with a history of injecting drug use in the hepatitis C testing environment. For this reason, the training should be developed and delivered by AIVL and its member organisations and provide a unique opportunity for health professionals to engage with members of the client group outside of the clinical setting. The training project should be conducted with partnership support from the relevant professional bodies in the hepatitis C testing and diagnosis service delivery environment.
- **Increasing access to peer support in the hepatitis C testing and diagnosis setting** – as research has demonstrated the positive impact that trained peer support workers can have on the willingness of people with a history of injecting drug use to undertake hepatitis C testing and diagnosis, opportunities for peer support in this context should be expanded. Available evidence from evaluations of previous hepatitis C peer support projects could provide suitable models and approaches. Support and resourcing to develop, pilot and evaluate new peer support models in this context should also be included. By ‘peer support’ AIVL means approaches developed and implemented by people with a history of injecting drug use who are affected by hepatitis C. Where pharmacotherapy treatment is a relevant factor, peer support workers should be people with current or past experience of pharmacotherapy treatment. Using trained and experienced IDU peers can assist in reducing fears of discrimination and creating a safe and comfortable testing environment for clients. It can also improve the quality of pre and post-test discussion and informed consent and can facilitate discussions on injecting drug use between physician and patient.
- **Improving access to specialist phlebotomy services and supervised self-collection of venous samples for people with a history of injecting drug use** - specialist phlebotomy services could be provided either through additional training, support and resourcing for existing pathology services and/or through specialist peers trained in venapuncture who could operate in a variety of primary health care settings (see recommendation to increase access to primary health care in the section on ‘Access to HCV Primary Prevention Services’ above). In addition to the above, AIVL recommends the development of policies and procedures to allow for greater supervised self-collection of venous samples among people who have a history of injecting use particularly those with few obvious accessible veins. This could be achieved through pilot initiatives in a range of hepatitis C testing settings with appropriate evaluation to allow for the development of best practice models and undertake appropriate risk assessment. AIVL would recommend the incorporation of trained peer support workers into the pilot programs to provide a level of supervision while still ensuring the barriers to testing identified above are removed.
- **Removing cost related barriers to hepatitis C testing and diagnosis among people with a history of injecting drug use** – it is recommended that research is conducted into the impact of associated or ‘hidden’ medical costs on access to ongoing monitoring of hepatitis C and anti-viral hepatitis C treatment assessment. This research should assess the increased health care access needs for people with complex and chronic conditions such as hepatitis C and drug dependency relative to their capacity to pay for such increased care needs. Issues examined should include the impact of increasing

consultation fees and concomitant reductions in access to bulk billing in general practice for those who are on limited incomes without healthcare card eligibility. Barriers to hepatitis C monitoring and diagnosis created by the increasing imposition of penalties and fees for missed appointments regardless of income level and the disproportionate impact of routine consultation fees on working people with chronic hepatitis C who are on a pharmacotherapy program with a community prescriber also should be included. The long term implications of illicit drug related poverty on the capacity of people with a history of injecting drug use to pay for health care regardless of whether they are currently employed needs to be appropriately considered within the proposed review.

iii. Hepatitis C Treatment and Management:

The accepted pharmaceutical treatment for hepatitis C in Australia is a combination anti-viral therapy involving pegylated interferon and ribavirin with a treatment duration period of 6 or 12 months depending on genotype. This form of hepatitis C treatment is subsidised by the Australian Government and is made available under the S100 Highly Specialised Drugs Program. Eligible patients must meet treatment access criteria under the S100 Guidelines. Prior to May 2001 current injecting drug users were excluded from accessing the government subsidised hepatitis C treatment as the S100 treatment access criteria required a patient to have been abstinent from injecting drug use for a period of 12 months prior to treatment. Despite the removal of this criteria people with a history of injecting drug use continue to face significant barriers to hepatitis C treatment.

There appears to be little formal data from people with chronic hepatitis C infection regarding both barriers to treatment and experiences of treatment. While there is research and writing documenting hepatitis C treatment issues or experiences from the perspective of treating physicians and other service providers, there is a paucity of formal evidence from the perspective of those contemplating, undergoing or with past HCV treatment experience. This is an interesting issue to note given the apparent ongoing levels of concern about low treatment numbers among people with a history of injecting drug use and the acknowledged complications for many people on HCV treatment particularly in relation to treatment-related side effects. This is highlighted by William Sievert in *Hepatitis C an Expanding Perspective*:

“Lack of attention to side-effects and contraindications can have potentially catastrophic outcomes for the patient and diminish their chances of achieving viral eradication. Both drugs [pegylated interferon and ribavirin] cause a plethora of side effects that have been well recorded in international registration studies conducted with close patient monitoring.” (Sievert, 2009)

One of the few studies that has documented the “consumer perspective” in relation to issues for people undergoing hepatitis C treatment and management is a monograph by the National Centre for HIV Social Research, Experiences of hepatitis C treatment and its management: What some patients and health professionals say. Key findings and issues raised by this important paper include:

- *Participants reported a wide array of physical and psychiatric side effects related to hepatitis C treatment;*
- *Support groups... reportedly assisted people during treatment. With support from health professionals such support groups using peer-based models were established which allowed patients to share with others their treatment experiences and strategies for coping;*
- *The most often cited reasons for patients discontinuing interferon-based treatment are the psychiatric impacts, which include depression, anxiety, lack of motivation, anorexia and paranoia; and*
- *Some people required little support or intervention during treatment while others needed intensive monitoring and assistance in order to cope* (Hopwood, 2006).

The paper repeatedly mentions the importance of close and appropriate support for the duration of treatment. This support must be available when required and may come from a range of people/areas including clinicians, family, friends, peers and clinic staff and must address physical, psychological and emotional needs for the patient to have the best chance of completing treatment. A key strategy for coping with treatment was the early implementation of support networks and preparation for treatment in terms of expectations, disclosure and coping strategies, all in the context of building a patient’s resilience (Hopwood, Treloar, et al, 2006).

The predominant aspect of peoples' experiences of treatment is the need for close emotional, physical and psychological support for the duration of treatment. This may well include 24-hour access to support, whether it be clinical, peer-based or other forms of support that are provided by a complete model of care. Support networks are key to building a person's resilience and must be implemented prior to the commencement of treatment in order to maximise a person's ability to endure and complete their treatment regimen. For many people with a history of injecting drug use, the knowledge that there are already established mechanisms for peer support which they can access without judgment or fear of disclosure of current or past drug use can make a significant difference to their decision making in relation hepatitis C treatment (Norman, 2008).

Understanding experiences of people on hepatitis C anti-viral treatment is critical to understanding and unpacking the barriers to hepatitis C management and treatment. Although there is not yet a large body of documentation on the experiences of people in HCV treatment, those experiences that are discussed travel quickly and extensively through peer networks – which are a highly trusted source of information particularly among people with a history of injecting drug use (AIVL, 2006). In the absence of more research studies and accurate information flowing to people with chronic hepatitis C infection, there is a significant risk of people only hearing the negative experiences of HCV treatment which can lead to myths and misinformation. This situation can lead people to not coming forward for ongoing management/monitoring of their hepatitis C (even without treatment) for fear that they will be forced into treatment or test results will make it necessary. The potential impact of only hearing negative hepatitis C treatment stories is highlighted by the following comment from a drug user who has recently completed treatment:

"You almost never hear from those people who have a relatively OK treatment experience. Sure some people have a really rough time, lots of bad side-effects, can't tolerate the drugs, etc, but sometimes it seems like you only hear the horror stories. At times before I started treatment it was almost like I was being warned off – and it nearly worked! My treatment experience was pretty good really and it has made me realise that some of us need to get out there and talk about getting through hep C treatment and how amazing that feels." (Peer report)

Barriers to Hepatitis C Treatment and Management:

This section will address the three inter-related areas of:

General/Overarching Barriers to Hepatitis C Treatment and Management

- General or overarching factors that can act as barriers to hepatitis C treatment and management for people with a history of injecting drug use;
- Barriers to hepatitis C treatment and management among existing service models; and
- Additional support and other issues relating to access to hepatitis C treatment and management.

Research is increasingly seeking to examine why the vast majority of people with chronic hepatitis C infection and a recent history of injecting drug use are not coming forward to commence treatment for hepatitis C (Hellard, 2009, Doab, 2005). As members of this affected community AIVL believes the question is not "why aren't people coming forward?" but "why would they?" People with a history of injecting drug use are contemplating a serious and complex form of treatment delivered through a health system that has frequently treated them poorly when they have been ill and where their own or others experiences have shown them that honesty in the clinical relationship can often result in punitive measures (Edlin, 2004, Crofts, 1997, Day, 2003, Seal, 2007).

People with a more recent history of injecting drug use are often also very fearful of the treatment and its potential side-effects and how both of these could impact on and destabilise their lives (Norman, 2008, Doab, 2005, McNally, 2004). As outlined above, added to this is the fact that many people are also dealing with multiple health and social issues including poverty, social exclusion, homelessness, the impact of criminalisation, problems with drug treatment access, etc, and therefore simply cannot find the space to prioritise hepatitis C within their lives (Hallinan, 2005, Falck-Ytter, 2002). Many people also have chronic infection but are not experiencing debilitating symptoms and this also makes it difficult to view medical treatment and/or support for their hepatitis C as a priority in comparison to other issues they may be managing (Doab, 2005).

Even if people are not coping with multiple health and social issues, like others in the community, people with hepatitis C can sometimes find their health just taking a 'backseat' in their lives. This may not be for any reason in particular and it may even be quite a sub-conscious process but the result nevertheless is one of inaction and lack of motivation to confront what is likely to involve a

difficult and unpleasant experience. For many people in this situation, they will be likely to stay in this place until their 'hand is forced' somehow by burgeoning symptoms, changing or poor liver function test results or serious illness.

For many the compromises and risks associated with hepatitis C treatment are considerable, even life-changing depending on how/if you respond to treatment and whether you are vulnerable to long-term side-effects. These are the issues that play on people's minds and inevitably at times, result in people delaying a decision about treatment and even ongoing monitoring until they are forced to confront the reality. This can be particularly pronounced for people who may not have used for many years and for whom hepatitis C is a constant reminder of decisions they made earlier in life.

In addition to the above factors, people can often feel quite overwhelmed by the large amount of information that is available on hepatitis C treatment. Anecdotal evidence from focus groups of current pharmacotherapy consumers who have undertaken hepatitis C treatment, showed that people felt they were being given "mixed messages" and "what appeared to be conflicting information" by health providers and community based organisations in relation to hepatitis C treatment, the potential for side-effects and likely treatment outcomes. This situation had led some people to perpetually delay making a decision about undertaking hepatitis C treatment because it seemed too difficult and people were unsure who to trust (Peer report).

This situation is often further compounded by the fact that for some people, even if they are experiencing hepatitis C-related symptoms, such symptoms often fluctuate so the decision to access treatment is postponed when their symptoms ease as the decision to go ahead seems so difficult and stressful to reach. Issues such as the need for long periods of treatment contemplation and the willingness to consider but not make a decision to commence treatment are also documented in the evidence (Norman, 2008, Doab, 2005, McNally, 2004).

A key factor raised by people on opioid pharmacotherapies in focus groups was that many had 'shelved' thinking about hepatitis C treatment because their daily experiences of the health system through their pharmacotherapy provider had convinced them that a 6-12 month treatment regime would simply be too stressful to contemplate. People talked about the "enivitable conflicts with people who have power over you" and the "constant moralising about pain relief". Those who had undertaken hepatitis C treatment

reflected on the personal stress of having to raise the issue of symptomatic relief of side-effects in the knowledge that the reaction was likely to be one suspicion about 'drug-seeking behaviour' rather than an assumption that you may genuinely need some assistance.

A number of people stated they had either just "struggled through regardless" and some had ended hepatitis C treatment prematurely because they could not cope with side-effects or perhaps more importantly, the response they would receive to them if they sought assistance. The issue of having side-effects (particularly those that required pain relief) dismissed and not taken seriously by health professionals was raised by a number of people (Peer report).

AIVL recognises that approaches to the issue of pain relief do vary from provider to provider and not all physicians or other health professionals will deny access to such medications for people with a history of injecting drug use. We also acknowledge that the management of treatment side-effects is a developing area and that clinicians at least, state that responses to treatment-related toxicity/side-effects management is improving (Dore, 2009b). Whether people's concerns about poor access to symptomatic relief are realised or not however, it seems expectations, and in some cases actual experiences of poor treatment, are having a direct impact on decision making in relation to commencing treatment and, for some whether they complete hepatitis C treatment. The assumption of drug-seeking behaviour and the denial of pain management and under-treating of pain to known drug users is also documented in the literature (Roberts, 2008, Morgan, 2006) and for this reason needs to be recognised and addressed for its potential to act as barrier to hepatitis C treatment.

Barriers to treatment for hepatitis C can be real or perceived and may exist at the level of the individual with hepatitis C or the clinical team providing the treatment service (Hellard, 2009). From the service provider point of view, barriers to treatment uptake for the individual tend to be seen almost exclusively in clinical terms, such as: lack of knowledge of treatment, its availability and eligibility requirements; the possibility of poor mental health while on interferon; alcohol use impacting on treatment outcomes; illicit drug use and ability to adhere to the treatment regimen and the potential for reinfection following treatment (Hellard, 2009).

At the level of the individual, some of the barriers to treatment can be the same for people with a history of injecting drug use as for other people with hepatitis C including:

- *Personal - individuals not being ready for treatment; being ill-informed about treatment; having negative attitudes towards orthodox medical treatment; and experiencing difficulties in making the necessary arrangements;*
- *Organisational/Institutional - lack of treatment places; waiting times; costs; inappropriateness of the services offered; and*
- *Societal - social stigma (Treloar, 2004).*

In a Victorian questionnaire administered to 659 people with hepatitis C, “the most common reason given for not seeking [hepatitis C] treatment was that they had not heard of it (33%). Other reasons participants identified included being concerned about treatment side effects, being told they were not eligible, and not being able to afford treatment.” (Stoove, 2005). This questionnaire was administered in 2000 and 2002, the 2000 component was conducted prior to the relaxation of eligibility criteria concerning current drug using status and both the 2000 and 2002 components were conducted prior to the relaxation of eligibility around prior treatment with interferon-based therapy for hepatitis C. In this regard, results today could differ considerably from those in 2000 and 2002. The study also found:

“Other factors that could contribute to low referral rates for current IDUs include HCV treatment and care taking a low priority among other social and health needs, the impact of ongoing drug use on the ability to meet appointments for both GP and specialist assessment and health care worker discrimination towards current IDUs” (Stoove, 2005).

A Victorian report looking into the challenges of hepatitis C treatment found that “there are a range of factors influencing decisions to commence treatment and adhere to treatment including economic factors, concern of side effects, concerns about the impact of compliance requirements on family and work commitments and perceptions of discrimination by treating staff.” The issue of side effects is important as “the effects of hepatitis C are sometimes not as significant for an individual as those of the treatment” which “makes the decision to begin treatment particularly difficult.” (McNally, 2004)

Practical barriers can be due to the individual’s personal circumstances. An example of this may be an individual’s living circumstances and whether that environment can

support them undertaking hepatitis C treatment. This might include not having access (or perhaps confidential access) to refrigeration for interferon storage particularly in communal or share housing arrangements. Others may be:

- Costs associated with transport to clinical appointments;
- Lack of personal or family support networks to assist with getting through treatment, helping out with meals, shopping and cleaning, etc;
- Concerns about the impact of hepatitis C treatment on parental responsibilities particularly if treatment results in side-effects such as depression;
- Concerns about losing employment and/or discrimination in the workplace if an intention to undertake hepatitis C treatment is disclosed;
- Difficulties in affording the costs associated with treatment particularly for the additional medications for side-effects management when people are already struggling to pay their weekly pharmacotherapy costs;
- Mistrust of the medical community due to past experiences of stigma and discrimination (Cooper and Mills, 2006).

As pointed out by Hopwood and Treloar, “in Australia, the medical profession is regarded as having conservative views about illicit drug use” and “this view is reinforced by decades of anti-drug messages and the explicit demonisation of drug users; elements integral to the prohibition message” (Hopwood, 2007). Research into the reasons why clinicians/service providers might be reluctant to refer or commencement an individual on hepatitis C treatment shows that service providers are concerned about:

- *The likelihood of side-effects and their potential severity;*
- *Whether the patient will tolerate and be compliant with treatment; and*
- *The long-term likelihood of the patient remaining free of hepatitis C, including the possibility of reinfection (Hellard, 2009).*

Further, McNally and Temple-Smith found that “specialist physicians rated the greatest hindrances to effective treatment to be a late referral, patients’ drug use and treatment non-compliance.” With respect to referral to specialists for treatment “75 percent of specialist

physicians were happy to accept a referral from a patient who currently injects, while a much smaller percentage of general practitioners (51%) were likely to refer a patient who is currently using drugs to a specialist" (McNally, 2004).

- **Barriers to Treatment - Injecting Drug Use Status:**

"Injection drug users constitute the core of the hepatitis C epidemic in the developed world... yet our efforts to control this pandemic have largely ignored the population in whom biology and epidemiology are being played out with the most devastating effects."

(Edlin, 2006)

In *Hepatitis C an Expanding Perspective* it is acknowledged that, although people who inject drugs comprise the vast majority of current and new infections, "there is a continuing reluctance to treat current injecting drug users". This is despite the fact that "in those studies where IDUs were compared with non-IDUs, the SVR rate for IDUs was often similar to, and on occasions higher than, that in non-IDUs". The point is further made that this unnecessary delay to treatment for many people who inject drugs is even more concerning when considered in light of the fact that "there is increasing evidence that early treatment of hepatitis C increases the likelihood of an SVR" (Hellard, 2009).

Treatment for hepatitis C in people who currently inject drugs is acknowledged as an area where treatment uptake is extremely low with over 90 percent of those who know they are hepatitis C positive have never received treatment. This situation continues despite the fact that best practice in the clinical setting recommends that decisions to treat individuals for hepatitis C infection should be made on a case-by-case basis rather than on assumptions about an individual's drug use or the likelihood of re-infection following treatment (Hellard, 2009). As far back as 2002, Edlin went to the heart of this issue and the extent to which assumptions about and poor attitudes towards people who inject drugs are acting as barriers to hepatitis C treatment when he stated:

"Much less is lost by treating a patient that does not adhere to therapy than by letting a patient progress to cirrhosis or death without a trial of treatment because of a prior assumption that the patient would not adhere to the regimen" (Hellard, 2009).

With regard to increasing the uptake of hepatitis C treatment, researchers, leading clinicians and advocates are now highlighting the urgent need to ensure that hepatitis C treatment is easily accessible to those who are most likely to be living with chronic infection – people with a history of injecting drug use. Further it has been acknowledged that without action to reduce barriers to hepatitis C treatment for people with a history of injecting drug use, there is little chance of hepatitis C treatment ever having a substantial impact on the morbidity and mortality related to hepatitis C (Hellard, 2009).

Although drug use can impact on treatment outcomes for some individuals (Sylvestre, 2007), drug use per se should never be a reason to preclude individuals from commencing treatment for hepatitis C infection. Although there is some evidence to show that some people become re-infected following a successful episode of hepatitis C treatment (Micallef, 2007) this is not the case for all people who inject drugs who undergo treatment and therefore should not be arbitrarily used to preclude otherwise eligible people from accessing treatment. Based on these factors, it is generally agreed that decision making in relation initiating treatment for HCV infection among people with a history of injecting drug use must be individually based on the whether the person wishes to initiate treatment, social factors that could impact on their treatment progression and outcomes and other medical comorbidities which may be relevant to their treatment.

Barriers to Hepatitis C Treatment and Management Among Existing Service Models:

In the past 10 years there has been major developments in the area of hepatitis C treatment including the removal of certain policy barriers to treatment such as removing exclusion criteria for people who are currently using illicit drugs and removing the pre-treatment liver biopsy requirement. Other improvements such as increased efficacy associated with combination therapy, more responsiveness to treatment side-effects and greater use of multi-disciplinary and collaborative care approaches have also been important developments. Many existing tertiary services have also been focusing on the development of approaches to improve the accessibility and quality of treatment such as the development and application of best practice standards and protocols, more focus on care pathways, greater attention to patient safety issues and increased participation in GP Shared Care and nurse-led models of service delivery.

Although these developments have undoubtedly had a positive impact on hepatitis C access and service

delivery in relation to treatment and management, not all tertiary services have engaged in these developments to the same degree. There are also a range of other issues that have not been addressed to the same extent and as a result, ongoing barriers to treatment remain. It is therefore with appropriate acknowledgement of the work that has been and continues to be undertaken by existing services that AIVL believes there is a need to identify and explore some of the ongoing environmental barriers that need to become the focus of additional efforts if we mean to further improve treatment access and service delivery particularly for people with a history of injecting drug use.

i. Tertiary Liver Clinics in Public Hospitals:

Access to government subsidised anti-viral therapy for hepatitis C is currently provided through specialist tertiary clinics in major public hospitals and some private medical specialists. Under the hospital-based liver clinic model, the individual undergoes testing and diagnosis to confirm chronic infection through a GP or other public health physician and is then referred to a specialist at the liver clinic. From assessment through to discharge following end of treatment, the individual is managed by liver clinic staff, which includes the treating specialist physician, as well as hepatology nurses and hospital pharmacists. Referral to hospital-based dieticians, social workers and psychiatrists is possible if such services are available and required. Following discharge from the liver clinic, the person's ongoing management is undertaken by their GP (Richmond, 2009).

Barriers to Hepatitis C Treatment in Tertiary Liver Clinics:

There are a series of both practical and environmental barriers to accessing hepatitis C treatment in specialist liver clinics in the public hospital setting. Although as stated above, some clinics have taken steps to reduce barriers to access and service delivery in relation to hepatitis C treatment, in some public hospitals, liver clinics are in fact larger gastroenterology units rather than being focused on the treatment and management of hepatitis alone or even focusing on liver-related conditions alone. In these instances, although hepatitis C may be a growing focus within the service due to the numbers of people living with chronic hepatitis C, the nature of the service is such that it is designed to address a diverse range of digestive and gastrointestinal conditions. While there are some advantages to this situation, it can also negatively impact on the accessibility of these clinics particularly for people with a history of injecting drug use. Given this situation, some of the major barriers to accessing hepatitis C treatment in the hospital-based liver clinic

environment include:

- **Finding the hospital-based liver clinic environment intimidating;**
- **Lack of flexibility in the service delivery model;**
- **Long waiting lists and too few treatment places; and**
- **Lack of peer support.**

Each of these barriers will be explored in more detail:

- **Finding the clinic environment intimidating** – the hospital-based setting can be very intimidating and forbidding for many people with a history of injecting drug use. While this of course varies depending on individual experiences within the health system, many people with a history of injecting drug use may have had little or no contact with hospital-based services and may also have had poor experiences with those health services they have accessed. The fact that liver clinics can be situated within larger gastroenterology units, where clinic staff may have very limited experience in working with people with a history of injecting drug use, can create further barriers to people feeling comfortable in the liver clinic environment. In this regard, the short-hand title of “liver clinics” can give people being referred to the service a false impression of the nature of the clinic and the specialist expertise of the staff particularly in understanding the needs of people who may be still using or on pharmacotherapies. The need for the unit to manage a high volume of referrals for a wide variety of complex and chronic conditions can restrict the clinic's capacity to respond to the specific needs of particular patients such as those people who are highly marginalised within society. People are scared about their condition and the prospect of treatment and are frequently coping with all of these issues without personal support systems due to family breakdown, early deaths of significant others and long-term social exclusion. These factors on their own can be sufficient to make the highly clinical environment of a hospital-based liver clinic overwhelmingly intimidating – a situation that is exacerbated if people find themselves sitting in a waiting room with people who make them feel inadequate and ‘other’. It should be made clear, it is not that AIVL is advocating a ‘ghettoising’ of people into specialised clinics that only treat those with a history of injecting drug use. We are however advocating the need for people to be adequately

prepared for the environment of the liver clinic and what they are likely to experience in that environment. We are also advocating the need for clinics to create environments and treatment approaches that are comfortable and relevant for highly marginalised patients rather than expecting the patient to 'cope' with and simply accept whatever is on offer.

- **Lack of flexibility in the service delivery model** – one of the other issues associated with accessing hepatitis C treatment through larger gastroenterology clinics is that it can significantly reduce the capacity for flexibility and responsiveness in the service delivery model. Most hospital-based gastroenterology units struggle with inadequate resourcing to provide quality services for a broad range of conditions. This situation greatly reduces their ability to tailor services and respond to the needs of particular patient groups. Research has shown that people with hepatitis C and a history of injecting drug use often require long contemplation periods (of months and years) in order to make a decision to commence hepatitis C treatment (Norman, 2008). Many people are likely to be dealing with a range of health and social issues and may be juggling multiple treatments, appointments and complex life situations. Larger gastroenterology units are not generally designed or resourced to provide the flexible, tailored approaches that work best for people with a history of injecting drug use. Some people will try to cope with this situation and will [silently] struggle to manage their own care thinking they do not deserve more tailored services and/or are fearful of what might happen if they are 'found wanting' and do not 'fit' the service/treatment model. Clinicians and other staff may not even be aware of these situations for people as those with a history of injecting drug use are often too ashamed and scared to disclose their full circumstances and needs to clinical staff for fear of being refused hepatitis C treatment. Whether they are actual or perceived fears, it is common for people with a history of injecting drug use to have a general lack of confidence in the way that clinical staff are likely to respond if you disclose your 'real situation'. The reality is that engagements with the health system (whether it is a regular GP appointment, a pharmacotherapy prescription renewal or an appointment at the liver clinic) too often becomes a 'performance piece' - an exercise in 'being whoever the service provider wants you to be' (or at least who you 'think' they want you to be) rather than ever being truly honest about your needs and situation. Unfortunately survival in both the illicit drugs market and within the health system have taught many people with a history of injecting drug use that honesty rarely results in a positive experience. It does however create a very stressful situation for people who are frequently self-managing multiple health and social issues with few people or services they feel they can really turn to for genuine, non-judgmental support.
- **Long waiting list and too few treatment places** – linked to the issue of inadequate resourcing for liver clinics is the barrier of long waiting lists and insufficient hepatitis C treatment places. Although AIVL acknowledges that funding for hepatitis C treatment places has increased over the past five years, these increases are woefully inadequate and as a result we are still only treating a fraction of the people eligible for treatment. While this is not an issue that is specific or unique to people with a history of injecting drug use, it is acting as an increasing barrier to hepatitis C treatment access for this group as we represent the people most affected by hepatitis C. Closely linked to this issue is the problem of poor clinician:patient ratios. While this is not a universal problem, it is certainly not an isolated issue either with some jurisdictions and regions identifying that a majority (and sometimes all) of their tertiary liver clinics do not currently meet the recommended ratio of 1 FTE clinician per 1000 hepatitis patients (Department of Health, Western Australia, 2009). The dual problems of a lack of funded hepatitis C treatment places and inadequate clinician:patient ratios are particularly acute in regional areas. The NUAA peer support worker for the ETHOS Project in the Hunter/New England area of NSW has also identified the issue of treatment places as one that needs to be carefully thought through and addressed before programs encouraging individuals to make decisions about hepatitis C treatment are implemented. Without adequate planning and service development, a situation very quickly develops whereby hepatitis C peer support workers can have people pro-actively seeking out treatment only to be frustrated by a lack of treatment places. This can have very negative repercussions for the peer support workers in terms of trust and credibility with their peers. From AIVL's perspective, there is a definite ethical dimension to this issue. Everything from *The National Hepatitis C Strategy 2010-2013* to state/territory strategies and plans are strongly advocating the need to increase access and uptake of hepatitis C treatment. While AIVL

welcomes the focus on providing people who need it and want it with access to quality care, it is absolutely essential that the level of funding for hepatitis C treatment is addressed as an integral part of any push to expand treatment access and uptake. This is particularly important for people with a history of injecting drug use as it is critical that people are not made more cynical or feel like even less of a 'priority' within the health system by having their expectations of hepatitis C treatment raised only to be told there are no treatment places available.

- **Lack of peer support** – we have left what we believe is one of the major barriers to accessing hepatitis C treatment through tertiary liver clinics to last as, in many ways, the current lack of peer support within these environments is contributing to many of the issues identified above (with the exception of the funding for treatment places and adequate clinician:patient ratios). Even those funding related issues however have a link to effective peer support as outlined above. AIVL is not aware of any public hospital-based liver clinic setting that currently incorporates peer support for people with a history of injecting drug use as a fully integrated part of the service delivery approach. Effective peer support cannot be provided by simply referring people to off-site community based organisations as most people will not pursue peer support through an external referral unless they have already had the opportunity to build a relationship with the peer support workers in that organisation and have the resources to travel to appointments/make phone calls, etc. For many people it can be difficult to appreciate the value of peer support until they have some form of direct, positive experience of accessing genuine peer support services. This is why it is extremely important for peer support options to be readily accessible on-site. This is also supported by the research highlighted above which has shown that early implementation of properly resourced, on-site peer support has the capacity to address many of the concerns that clinicians identify as the reasons why they are reluctant to treat injecting drug users.

There are a range of peer support models that can be provided in the liver clinic context including peer support workers (to provide one-on-one support for individuals), peer support groups (which can be self-facilitated or organised by staff at the service), peer support workshops, etc. These on-site peer support options can also be supplemented with online peer

support and information sites (for those who may wish to access certain information or discuss particular issues more anonymously) and by making peer-based publications and resources available in the clinic reception and at consultations. Examples of successful on-site peer support models for people with a history of injecting drug use are provided in the "Models of Access and Clinical Service Delivery" section of this paper. An example of online peer support sites is AIVL's recently launched "Our C-Ciety" - an online peer support forum for people with a history of injecting drug use who are contemplating, undertaking or have recently completed hepatitis C treatment. "Our C-Ciety" can be accessed by people with a history of injecting drug use via the AIVL website. AIVL and its member organisations also produce magazines, hepatitis C treatment resources and information materials that are all written by and for people with a history of injecting drug use. Community-based hepatitis C support workers can provide valuable off-site information for people during the hepatitis C treatment process but this should not be confused with or viewed as a substitute for genuine peer support.

Regardless of the peer support model used, it is essential that peer support in the hepatitis C treatment environment is designed and provided by and for individuals and organisations who are accepted as peers by the patient group. Depending on the diversity of the patient group within a given liver clinic (particularly large gastroenterology clinics) it may be necessary to have a range of peer support options available. It should be noted however that peer support is most often needed by more marginalised and vulnerable patients who may not have existing family and/or friendship networks to support them during the treatment process. Based on the profile of the epidemic, if resources are limited a priority focus on providing peer support for people with a history of injecting drug use is appropriate as many people in this group are likely to have significant support needs and may not have access to family support networks. For further discussion on approaches to, the evidence for and benefits of hepatitis C peer support, see the "Models of Access & Clinical Service Delivery" section of this paper.

Addressing Barriers to Access and Service Delivery in Liver Clinics:

Peer Support:

- **Peer Support Models** – AIVL advocates the development and implementation of tailored peer support approaches as a fully integrated component of a multi-disciplinary team

approach. AIVL believes properly resourced, supported and designed peer support models will significantly reduce a number of the barriers to treatment in the liver clinic setting identified above including:

- » reducing the intimidating nature of the hospital environment;
 - » challenging negative stereotypes and poor attitudes among clinical and non-clinical staff;
 - » providing more flexible and responsive service models;
 - » assisting patients to develop their levels of health literacy and gain a better understanding of the 'liver clinic' environment;
 - » supporting patients in their clinical interactions including acting as a 'translator' or 'go-between' particularly on sensitive issues;
 - » supporting people through the treatment contemplation phase and reducing treatment anxiety;
 - » assisting people to meet their needs and requirements for hepatitis C treatment eligibility particularly on issues that people are unlikely to raise with clinical staff; and
 - » reduce the workload of clinical staff which can potentially provide more capacity for assessment and treatment management.
- **Peer Support Resourcing** - Peer support for people with a history of injecting drug use in the liver clinic setting must be adequately resourced and supported with formal linkages to the relevant drug users organisation in order to provide appropriate models and adequate supervision and support for peer support workers.
 - **Workforce Training & Support** - All clinical and non-clinical staff within liver clinics should undertake training on a regular basis in relation to stigma and discrimination and attitudes and values towards people with a history of injecting drug use.
 - **Reviewing Service Delivery Models** - given the level of hepatitis C infection among people with a history of injecting drug use there needs to be research and evaluation into appropriate models

of service delivery in hospital-based liver clinic settings for this patient group. This should be aimed at reduce practical and physical barriers in the clinic environment and must be conducted in consultation with peer-based drug user organisations.

- **Resourcing for Hepatitis C Treatment** – there is an urgent need for increased funding for the number of government subsidised treatment places and to improve the clinician:patient ratio in hepatitis C treatment in hospital-based specialist liver clinics. The lack of treatment places is acting as a fundamental barrier to hepatitis C treatment access for people with a history of injecting drug use particularly as some clinicians are already reluctant to treat drug users.

ii. **GP-Shared Care Models:**

The shared care model of treatment for people with hepatitis C involves an arrangement between a general practitioner accredited to prescribe pharmaceutical drugs for the treatment of hepatitis C and a specialist from a liver clinic at a public hospital. An individual with chronic hepatitis C is referred to a specialist by a general practitioner. The specialist then refers that individual with hepatitis C on to an accredited (S100 prescribing) general practitioner who then manages their care in collaboration with the referring specialist (Spina, 2007). In the evaluation of the NSW/ACT Hepatitis C Community Prescribing Pilot which trialled a model of GP shared care for hepatitis C treatment, the rationale for the model was given as:

...to increase access to hepatitis C treatment to enable the health system to cope with an anticipated increase in demand for treatment... This anticipated increase in demand is due to the numbers of patients infected with hepatitis C and the improved efficacy of treatment (Spina, 2007).

The evaluation also highlighted that the pilot had a significant impact on increasing the skills of GPs in understanding hepatitis C treatment and managing people on treatment. GPs were also supportive of community prescribing but critical of the restriction on their ability to initiate hepatitis C treatment and stated that future models should recognise the pivotal role of nurses in supporting both patients and community prescribers. Overall, the evaluation of the NSW/ACT Hepatitis C Community Prescribing Pilot demonstrated that community prescribing of HCV S100 treatment

was both administrative and clinically feasible (Spina, 2007).

Following the cessation and final evaluation of the above HCV community prescribing pilot in 2007, an ongoing program of shared care was endorsed by the Highly Specialised Drugs Working Party. NSW Health has funded ASHM to roll out the hepatitis C community prescriber program (shared care) in NSW. The conditions of the shared care program are the same as the preceding pilot, i.e. that the prescriber must be linked to a specialist affiliated with a hepatitis C treatment clinic at a public hospital and the specialist must initiate treatment. HCV prescribers are authorised to write second and ongoing scripts which must be dispensed from a public hospital pharmacy. (www.ashm.org.au)

Given the extremely low numbers of people currently undertaking treatment for hepatitis C, many in the hepatitis C treatment area are looking to shared care arrangements to expand access particularly for people who are marginalised and may be reluctant to access treatment in the liver clinic environment alone:

Many patients develop a therapeutic relationship with their GP that spans many years, therefore, shared care arrangements between GPs and medical specialists have evolved to accommodate the patient's need to access hepatitis C care in a geographically convenient and familiar environment... It is anticipated that the provision of antiviral treatment through GP clinics will increase access, particularly among marginalised communities such as people with drug and alcohol addiction, and those in rural and remote communities. (Richmond, 2009)

As this paper is being written, the use of GP shared care arrangements for hepatitis C treatment are expanding. A number of states have recently provided funding for shared care models that employ nurses often clinical nurse consultants (CNCs) or practice nurses to assess patients, liaise with liver clinics and to conduct community contact work in relation to the particular shared care initiative. This provides a link from more remote (physically and/or socially) communities to GPs and then to specialist physicians. This version of the GP shared care model has only recently been initiated but is increasingly being seen as a way to improve the capacity and reach of general practice in relation to hepatitis C treatment.

Queensland Health is one of the jurisdictions which

has recently initiated and evaluated a new Hepatitis C Shared Care Initiative. This initiative has involved implementing a shared care approach within ten public hospital liver clinics across Queensland and has been evaluated as successfully increasing access to hepatitis C treatment and management in the community. It has challenged the current treatment process by shifting treatment from specialist liver clinics to shared care with general practice. Although the initiative has only been operating for a little over two years and is still evolving, the evaluation has identified a range of important issues and questions about developing GP shared care arrangements for hepatitis C treatment particularly at the state-wide level including:

- The degree to which shared care models need to be embedded within specialist liver clinics;
- The need to have a flexible approach to the development of specific shared care models depending on geographical, cultural and health sector contexts;
- The issues associated with employing CNCs and practice nurses that do not have backgrounds working in hepatitis C and the associated training and clinical implications – particularly in rural and regional areas where it is less likely to find CNCs with hepatitis C backgrounds;
- The differences between metropolitan and rural clinics in relation to patient mix, resources available, expertise within the clinic and access to bulk billing GPs and other allied health services, etc;
- The implications for increasing treatment access if there is a liver specialist 'in-house' as opposed to a 'fly-in' specialist;
- The benefits that can come from employing one or more practice nurses in addition to CNCs so that CNCs could focus mainly on recruiting GPs to the initiative as well as patient assessment and liaison with the clinics; and
- The impact that funding positions for psychosocial support can have on providing access to hepatitis C treatment for those people who were previously considered as 'complex patients'.

(McNally, 2009)

Barriers to Hepatitis C Treatment in GP Shared Care:

Some of the major barriers to accessing hepatitis C treatment and management under GP shared care arrangements are:

- **Very slow to roll-out GP shared care models;**
- **Model relies on GP availability and willingness to treat people for hepatitis C;**
- **Lack of access to GPs particularly in regional and rural areas;**
- **Concerns if GP is also the individual's pharmacotherapy prescriber; and**
- **Lack of peer support.**

Each of these barriers will be explored in more detail:

- **Very Slow Roll-Out of GP Shared Care Models** - Given the number of evaluations showing the potential for GP shared care models to increase access to hepatitis C treatment, the seemingly very slow rollout of the model across all jurisdictions has been somewhat surprising. While it is recognised that most jurisdictions are now implementing or in the process of developing GP shared care models of access and service delivery, it is also acknowledged that there is still considerable work to be done to ensure that the role of community based care for hepatitis C treatment can be fully realised. In particular, there is a need for greater investment in GP shared care models to support training of GPs in hepatitis C treatment and management, fund practice nurses, nurse practitioners (NPs) and CNCs within general practice settings and to encourage interest from GPs in increasing their role in managing people in hepatitis C treatment. Increasing access to hepatitis C treatment through shared care arrangements between general practice and specialist clinics is particularly important given the documented concerns from people with hepatitis C that hospital-based liver clinics can be intimidating and the very long waiting lists (of months, even years) to access treatment in many clinics.
- **Increased Reliance on GP Availability and Willingness** – one of the issues that has been identified in the evaluations and policy papers focused on GP shared care models has been the need for GPs participating in such approaches to have sufficient expertise in hepatitis C treatment and management. This is an important issue for a GP workforce that is often described as overworked (McNally, 2009) and where willingness to participate in hepatitis C treatment can be an issue associated with attitudes towards people with a history of injecting drug use (Parr, 2010). This is also supported by the evaluation of

the Queensland GP Shared Care Initiative in which CNCs found some GPs to be non-responsive, hard to contact, defensive and over-worked (McNally, 2009).

Anecdotally people with hepatitis C and a history of injecting drug use have also raised concerns about whether GPs have the time and interest to develop sufficient expertise on hepatitis C treatment and management - particularly if the contact with the specialist is minimal due to geographic location, existing patient loads at liver clinics, etc (Peer report). This general lack of confidence in having hepatitis C treatment managed largely in the general practice setting can stem from poor hepatitis C testing and diagnosis experiences particularly for people on opioid pharmacotherapies through a community prescriber. The negative impact of poor testing experiences on treatment is explored in the section on "Barriers to Hepatitis C Testing & Diagnosis" above. It should be noted however that not all people with hepatitis C have concerns about being treated within general practice with patients treated through the NSW/ACT community prescribing pilot stating they felt well supported by their GP (Spina, 2007). Regardless of individual preferences and experiences however, it is essential that GP shared care initiatives include a sufficient focus on training and professional development for GPs to develop the necessary skills to manage hepatitis C treatment particularly for people with complex comorbidities and multiple social issues. In this regard, AIVL supports the recommendations of the evaluations of GP shared care approaches which highlighted the need to ensure training, accreditation and S100 prescriber support based on national competency standards (Spina, 2007).

- **Lack of Access to GPs** - Evaluations of GP shared care models have highlighted difficulties associated with attracting particularly bulk billing GPs to the initiatives. A lack of bulk billing GPs can act as a significant barrier to hepatitis C treatment for people with a history of injecting drug use. People on opioid pharmacotherapies through a community prescriber who are employed and ineligible for a health care card, are already paying regular consultation fees (often fortnightly or monthly) for pharmacotherapy prescription renewals as well as pharmacy-based pharmacotherapy fees. As outlined above, many GPs are also now introducing fees for late and

missed appointments that must be paid in full before further appointments will be made. While some GPs will offer bulk billing for people on hepatitis C treatment (even if they do not have a health care card) this is usually offered on an adhoc rather than standardised basis. In the absence of guaranteed bulk billing, undertaking hepatitis C treatment through a GP shared care arrangement can simply be prohibitive for many people with a history of injecting drug use. This can be further compounded with the cost of multiple additional medications for managing treatment side-effects and travel costs associated with appointments. In many areas particularly regional and rural settings, it can also be very difficult to get a timely appointment with a specific GP or in some cases, any GP. This can be made worse by the fact that many of the GPs who are willing to engage in shared care arrangements for hepatitis C, are also opioid pharmacotherapy prescribers which can make it even more difficult to access them for short-notice appointments during complex hepatitis C treatment management.

- **Concerns if GP Prescriber is also Pharmacotherapy Prescriber** – the issues associated with a GP participating in hepatitis C shared care arrangements and also being an individual's pharmacotherapy prescriber mostly relate to communication problems and concerns about honesty in the treatment process. These issues are outlined in the section below relating to "Hepatitis C Treatment in Pharmacotherapy Settings". For these reasons they will not be covered further here other than to reiterate the importance of honesty in the hepatitis C treatment process and the need to take potential communication problems seriously.
- **Lack of Access to Peer Support** – the lack of peer support in GP shared care arrangements is a major concern for all the same reasons as identified in the liver clinic settings above. AIVL is currently unaware of a genuine peer support approach being included in a general practice setting in any jurisdiction. While GPs participating in hepatitis C treatment shared care arrangements do refer patients to off-site community-based (and sometimes peer-based) organisations for additional information and support during treatment, peer support has not yet been fully integrated into any of the GP shared care pilots or any ongoing GP shared care arrangements. As with the liver clinics settings, properly funded and supported peer support can address many barriers to access and service

delivery. Unique to the GP setting however is the fact that although general practice is part of the health system, it is at the end of the day a private business rather than part of the 'public' hospital system like liver clinics. This changes the context for peer support particularly for people with a history of injecting drug use.

The section on "Peer Support Models" earlier in this paper outlines the evidence for and benefits of peer support by and for people with a history of injecting drug use in relation to hepatitis C treatment. Some of the essential components are that such peer support needs to be provided by other people with a history of injecting drug use, must be fully integrated into the service model and must be adequately resourced and supported particularly through a formal link with local peer-based drug user organisations. For peer support to work in the general practice context workers must be able to openly identify as 'peers', must be supported to operate as a full member of the practice team and must be properly paid and provided with support and supervision (through a formal link with the local drug user organisation). All of these essential components will be challenging to guarantee in the general practice setting. AIVL has concerns about the potential for peer support workers to be treated poorly in the general practice setting due to stigma and discrimination against people with a history of injecting drug use. Having said this however, it is important to acknowledge that such attitudes vary considerably from one practice to another and in this regard, AIVL believes the first stage in incorporating quality peer support models into the general practice setting would be to identify a number of willing GPs to participate in pilot projects. Such pilots could identify the essential components of an effective hepatitis C treatment peer support model in the general practice context and develop strategies for addressing challenges to the peer support approach in this unique environment.

Addressing Barriers to Hepatitis C Treatment in GP Shared Care:

- **Greater Investment in GP Shared Care Arrangements** - there is a need for greater investment in GP shared care models including funding to:
 - » Support training of GPs in hepatitis C treatment and management;
 - » Engage hepatitis C focused practice nurses, nurse practitioners (NPs) and CNCs within general practice settings;
 - » Employ hepatitis C treatment peer support workers in the general practice setting; and

- » Encourage greater interest from GPs in increasing their role in managing people in hepatitis C treatment.

Peer Support:

- **Peer Support Models** – there is a need to conduct pilot peer support projects within a range of general practice settings with the aim of developing and documenting suitable models for effective hepatitis C treatment peer support within general practice. AIVL believes properly resourced, supported and designed peer support models will significantly reduce a number of the barriers to treatment in the general practice setting including:
 - » Increasing the willingness of general practice to participate in shared care arrangements for hepatitis C treatment;
 - » Increasing the effectiveness and cost-effectiveness of nurse-led models of care (practice nurses, NPs and CNCs) by providing them with more time to focus on assessing patients, supporting GP clinical management, liaising with the liver clinic, developing linkages, etc;
 - » Challenging negative stereotypes and poor attitudes among GPs and other practice staff by having acknowledged ‘peers’ on staff;
 - » Providing more flexible and responsive service models by using peer support workers to facilitate referrals to allied health services and community-based organisations;
 - » Supporting patients in their clinical interactions including acting as a ‘translator’ or ‘go-between’ on sensitive issues with the GP and specialist;
 - » Supporting people through the treatment contemplation phase and reducing treatment anxiety;and
 - » Reducing concerns about undergoing hepatitis C treatment with a GP who is also your pharmacotherapy prescriber by using the peer support to assist with communication issues.
- **Peer Support Resourcing** - Peer support for people with a history of injecting drug use in the general practice setting must be adequately

resourced and supported with formal linkages to the relevant drug users organisation in order to provide appropriate models and adequate supervision and support for peer support workers.

- **Workforce Development** – there are a range of workforce development issues that need to be implemented to address existing barriers to GP shared care including:
 - » Development and implementation of a national training, accreditation and S100 hepatitis C treatment prescriber support program based on national competency standards;
 - » In addition to hepatitis C treatment and management skills, accreditation for S100 community prescribers should include training to address stigma and discrimination and negative attitudes towards people with a history of injecting drug use; and
 - » All nursing and non-clinical staff in practices delivering hepatitis C treatment through GP shared care arrangements should be required to undertake initial and follow-up training on stigma and discrimination and providing non-judgmental services to people with a history of injecting drug use.
- **Increasing Access to Bulk Billing Arrangements During Hepatitis C Treatment** – poor access to bulk billing GPs has been identified as an increasing barrier to the successful delivery of hepatitis C GP shared care arrangements (McNally, 2009). There is a need for a special purpose funding arrangement under Medicare to support GPs bulk billing for consultations associated with hepatitis C treatment and management for people with a history of injecting drug use (no health care card needed). The current health system reform process could provide a unique opportunity to address this issue by developing realistic funding options to support greater participation in shared care arrangements among general practice. Such arrangements need to find the balance between the financial needs of general practice and the financial capacity of marginalised patients.
- **Improving Access to GPs** – there is an urgent need to utilise the current health system reform process to improve access to GPs particularly in regional and rural contexts. This issue is already fundamental to the aims of the health system

reform process but needs to be considered specifically in the context of managing complex and chronic conditions including hepatitis C among people with a history of injecting drug use. Improving the capacity of people on hepatitis C treatment to get a timely appointment with their GP as required during hepatitis C treatment is essential to the ongoing successful development and implementation of GP shared care arrangements. This is a major structural issue for the health system and although this recommendation is focused on access to GPs in context of hepatitis C treatment shared care, ultimately the problem will only be adequately addressed through a broader solution to the ongoing GP shortage.

iii. GP Initiated Hepatitis C Treatment Model:

This model is currently in the pilot stage and only operating in three locations across NSW (Sydney, Orange and Cowra). A total of five GPs are involved in the program, with more to be trained from November 2010. The model is aimed predominantly at people with genotype 2 or 3 hepatitis C. Genotype 1 patients can be referred to a GP participating in the program by a liver specialist, but a program GP cannot initiate treatment for people with genotype 1. The model is well-planned throughout the duration of treatment, with GPs working to an algorithm and protocol that dictates reviews, testing, etc. The treatment initiating GP provides ongoing care post-treatment as necessary. Specialists have minimum contact with the patient, particularly if treatment proceeds smoothly and with few complications/side effects. One of the main aims of moving to GP initiated hepatitis C treatment models is to further reduce treatment waiting lists and expand access to and uptake of hepatitis C treatment in the community.

Barriers to Hepatitis C Treatment with GP Initiated Care:

Many of the barriers to treatment with GP initiated care are not surprisingly very similar or the same as those outlined above in relation to GP shared care reliance on the treating GP. For this reason, all of the recommendations above should be applied in the context of GP initiated treatment including the need for piloting of peer support models to enhance access to and uptake of treatment and the quality of care provided.

iv. Hepatitis C Treatment in Pharmacotherapy Settings:

It is acknowledged that providing treatment for people with hepatitis C in pharmacotherapy settings has the

potential to increase access to and uptake of hepatitis C treatment. Research has found that “clients and health professionals viewed hepatitis C treatment in OST [Opiate Substitution Therapy] as a one-stop-shop model which could increase access to and uptake of treatment and build on existing relationships of trust between OST client and health professional.” Further, “OST clients reported that if HCV treatments were offered at their OST clinic they would be more likely to commence treatment as it would provide a convenient ‘one-stop-shop.’” (Treloar, 2010b)

The Healthy Liver Clinic model referred to elsewhere in this paper, featured a multidisciplinary approach in which a peer supported model of hepatitis C treatment access was piloted in a large metropolitan pharmacotherapy service. The peer support worker played a prominent role in initial screening, prevention education, assessment for antiviral treatment readiness and support during treatment and with comorbidities and treatment side effects (Brogan, 2008). The evaluation of the pilot provides an overview of how the HLC operated:

- *The HLC team consisted of sessional medical practitioners, a visiting specialist physician, peer worker, nurse and pharmacist, with access to other allied health professionals as required;*
- *Patients undergo a comprehensive assessment of their substance use, medical, psychiatric and psychosocial conditions prior to commencing HCV treatment, and have regular clinical review;*
- *There [was] a weekly after-hours support group facilitated by HLC staff; and*
- *A peer education officer... [provided] a fundamental role in the on-going support of HLC clients prior [to], during and following their treatment schedule. The engagement of a peer worker in the HLC aimed to facilitate referrals and recruitment to the service, provide support to people considering and undergoing treatment and enhance patient adherence and support within the service (Norman, 2008).*

Since the demise of the HLC model, access to this form of integrated and intensive hepatitis C treatment peer support in conjunction with opioid pharmacotherapy settings is now only offered through the ETHOS (Enhanced Treatment for Hepatitis C in Opiate Substitution Settings) study. ETHOS is trialling hepatitis C treatment in drug treatment settings in a number of locations across NSW. As of April 2010, 66 people had been enrolled in the ETHOS cohort with just 30 percent of these having commenced treatment (Gillman, 2010). It is important to note however, that

the peer support components of the study have only commenced quite recently and the potential impact of these initiatives are therefore not reflected in the above data. As outlined in the earlier section on “Peer Support Models”, initial data from those ETHOS sites which have added peer support components is very promising in relation to increased levels of engagement and treatment uptake, but as yet no formal evaluations have been published.

A model of treatment in Vancouver, Canada utilised a hepatitis C treatment peer support group as a means to inform and recruit people into treatment, as well as support them during and post treatment. People with hepatitis C were asked if they would like to attend the peer support group initially as an introduction to treatment and others’ experiences of treatment. In this manner, a high percentage of people with hepatitis C were recruited into treatment. The clinic provided multidisciplinary care (including methadone maintenance therapy, NSP and counselling) with “up to seven physicians, four registered nurses (including a dedicated HCV research nurse), six drug and alcohol counsellors and on-site infectious disease specialists” (Grebely, 2010). The project’s report reflects on some of the benefits of using group-based peer support to improve access to and uptake of hepatitis C treatment in pharmacotherapy settings:

“...the peer-based HCV support group is a model that has allowed us to engage and provide care and treatment for HCV infection in a large number of drug users, the majority of whom have multiple potential barriers to intervention. Peer support allows educational material to be tailored to individual knowledge levels, improves clinical attendance and encourages cooperation with medical recommendations. It is also a powerful influence for those who attend regularly, moving between the emotional, educational and social support level. Patients begin to improve in other areas of their lives including general physical health (e.g. nutrition), mental health and addiction and improved social status (e.g. stable housing, education and employment). The results from this study show that a peer-based HCV support group can fit within the constraints of other settings and can be a powerful tool to significantly improve access to HCV care among current and former

illicit drug users who may already be engaged in care for reasons unrelated to HCV infection.”
(Grebely, 2010)

For people in opiate pharmacotherapy treatment (OPT) who have hepatitis C, the barriers to hepatitis C treatment are often complex and multi-faceted. In this context, research into providing hepatitis C treatment in pharmacotherapy settings has highlighted that “providing hepatitis C treatment – effective, successful treatment, that is – in OPT programs is likely to require careful rethinking of the overall design and delivery of those programs.” (Treloar and Fraser, 2009) While surveys of pharmacotherapy clients reveal a willingness to consider hepatitis C treatment, many people are declining treatment for a wide variety of reasons. These include concern over side effects of the drugs used, not feeling sick enough to require treatment, other health priorities, a lack of awareness of treatment and its efficacy, and other pressing issues such as housing, finances, criminal justice issues, etc. (Treloar and Holt, 2008)

While the ‘one-stop-shop model’ of hepatitis C treatment in pharmacotherapy settings will have appeal for some people, on some pharmacotherapy programs, it is equally important to recognise that not all people with hepatitis C on pharmacotherapies will want to undergo hepatitis C treatment in their pharmacotherapy setting. The current rush to incorporate hepatitis C treatment into pharmacotherapy settings as a ‘solution’ to low hepatitis C treatment numbers among people with a history of injecting drug use belies the reality of the pharmacotherapy treatment experience for many people on these programs.

Some people prefer to keep their drug dependency treatment separate to the management of other health conditions. Concerns about the potential for breaches of confidentiality and being judged by others can be major reasons why people prefer to undergo treatment for hepatitis C away from their pharmacotherapy setting (Treloar, 2010b). For others there are concerns about whether their pharmacotherapy provider and the other staff employed in the service have sufficient expertise and interest in hepatitis C for them to feel confident accessing hepatitis C treatment in that environment. Concerns about the culture of some pharmacotherapy services and whether the overall design of the program lends itself to a responsive, flexible and supportive hepatitis C treatment experience are also questions for some pharmacotherapy consumers.

In this context, the paper in Drug & Alcohol Review by Treloar and Fraser titled *Hepatitis C treatment in pharmacotherapy settings: Increasing treatment*

uptake needs a critical view, provides a cautionary tale when considering providing hepatitis C treatment in pharmacotherapy settings:

“The proposal that hepatitis C treatment be offered through OPT depends for its viability on the character of those services and the attitudes and expertise of the staff... OPT clinics often entail elements not suited to therapeutic environments for hepatitis C treatment... In general, there is an urgent need to consider ways in which clinics can be redesigned to provide a secure, supportive environment if they are to take on the additional role of delivering highly taxing treatment for hepatitis C... the rigours of [hepatitis C] treatment mean compliance and completion rely to some extent on the support and goodwill of treatment providers. It is not yet clear that OPT programs are equipped, either institutionally or in terms of informal staff culture, to provide this support (Treloar, 2009).

Barriers to Hepatitis C Treatment in Pharmacotherapy Settings:

Although access to opioid pharmacotherapies is recognised as assisting some people to better prioritise hepatitis C within their lives and potentially contemplate and/or undertake hepatitis C treatment, its simultaneous role as a potential barrier to rather than facilitator of hepatitis C treatment has not been sufficiently explored in the literature. The reason pharmacotherapies can act as a barrier to hepatitis C treatment has nothing to do with the efficacy of the opioid treatment/medication itself but rather the way that pharmacotherapy treatment is currently structured and delivered. This is particularly important given the increasing focus on providing hepatitis C treatment in pharmacotherapy settings. The perceived benefits of the ‘one stop shop’ approach could be undermined if pharmacotherapy programs are unable or unwilling to adequately incorporate the needs of people on hepatitis C treatment into the program’s operations and environment.

Inflexibility in the program design and approach is one of the major problems continuously identified in research by people on opioid pharmacotherapies (Treloar, 2004). Concerns on behalf of health departments about the diversion of pharmacotherapies to people not registered on a program and issues related to child safety and

accidental consumption of dispensed medications, have led to highly restrictive policies particularly in relation to take home doses. While extremely limited access to unsupervised dosing causes ongoing difficulties for people accessing the program, there are particular implications of this highly restrictive system that can also act as a disincentive and barrier to hepatitis C treatment for people on on pharmacotherapies.

While it is acknowledged that policy and administrative decisions relating to the design and delivery of opioid pharmacotherapy programs occur at the state/territory level, the policies in each jurisdiction have a range of important aspects that are broadly consistent across the country. Some of these aspects relate to the specific limitations within the program as well as workforce culture issues that are acting as direct and indirect barriers to hepatitis C treatment contemplation and uptake among pharmacotherapy consumers including:

- **Lack of increased take aways during hepatitis C treatment;**
- **Punitive nature of pharmacotherapy program design and delivery;**
- **Increasing cost of pharmacotherapy treatment;**
- **Poor access to pain management and symptomatic relief of side-effects;**
- **Concerns about confidentiality;**
- **Lack of knowledge and expertise on hepatitis C;**
- **Lack of pharmacotherapy options;**
- **Lack of peer support.**

Each of these barriers will be addressed in more detail:

- **Lack of Increased Take Aways During Hepatitis C Treatment** – for the reasons outlined above access to pharmacotherapy take away/home dosing is strictly regulated in all jurisdictions. While the maximum number of take away doses per week varies between jurisdictions and between methadone and buprenorphine, being given flexible access to increased take away doses would be extremely unlikely for the majority of people on pharmacotherapies who are contemplating or undergoing hepatitis C treatment. This lack of flexibility regardless of individual circumstances can act as a barrier to people undertaking hepatitis C treatment due to concerns about how they will manage their ‘in-

clinic dosing' if they experience treatment side-effects. For people not on pharmacotherapies it may not sound particularly onerous to consider travelling to the clinic/pharmacy between two and seven times a week (depending on the level of take away doses). For people who are experiencing hepatitis C treatment side-effects however attending for dosing could act as a significant barrier to treatment if the side-effects are serious and/or the person is experiencing multiple side-effects particularly nausea, vomiting, extreme fatigue, serious headaches, etc. Opioid pharmacotherapies are drugs of dependence which means missing more than a single dose due to being too ill to attend the clinic/pharmacy is not really an option for most people. Although there is usually a degree of discretion available to the treating doctor within current pharmacotherapy policy guidelines at the jurisdictional level, it would be rare for a prescriber to approve additional take away doses outside of policy parameters for more than one-off circumstances or very short-term periods (e.g. days rather than weeks or months). In addition, anecdotal reports suggest that people who have undertaken hepatitis C treatment and sought extra regular take away doses due to problems with treatment side-effects have been met with distrust and assumptions of 'drug-seeking behaviour' rather than genuine need, even for otherwise very 'stable' patients (Peer report). Experiences such as these travel through peer networks and are acting as potential barriers to treatment contemplation, uptake and completion.

- **Punitive Nature of Pharmacotherapy Program Design** – strongly linked to the above issue of poor access to extra take away dosing during hepatitis C treatment is the problem of how 'missed doses' are managed within the current program framework. The majority of pharmacotherapy programs have strict rules on ceasing dosing until a new prescription has been acquired following multiple missed doses (generally 3-5 days). While it is unlikely someone would be removed from the program if they could provide evidence of illness related to hepatitis C treatment, people have been forced to see their prescriber to obtain a new prescription before redosing can commence when they have missed multiple doses due to complications associated with hepatitis C treatment. This lack of flexibility can act as a further stress for people undertaking hepatitis C treatment and act as a barrier to those considering it.
- **Increasing Cost of Pharmacotherapy Treatment** – there is now increasing evidence of the negative impact the cost of pharmacotherapy treatment is having on the lives and health of people on the program (Rowe, 2008, Feyer, 2010). In some states people are now paying upwards of \$80.00 per week with \$35.00-\$40.00 per week an average payment for many pharmacotherapy consumers (AIVL, 2010b). The only exception to this is the ACT where pharmacotherapy treatment is government subsidised and consumers pay a maximum of \$15 per week. How much people are paying for their pharmacotherapy can be an important issue when it comes to improving access to hepatitis C treatment for people on pharmacotherapies. For some people commencing hepatitis C treatment also means having to cut work hours which is accompanied by an associated drop in income. Given the role of pharmacotherapies in people's lives, it is unlikely people will make the decision to commence hepatitis C treatment if it was to threaten their access to their pharmacotherapy in any way. In this regard, the increasing cost of pharmacotherapy effectively removes the option of people taking a break from work or reducing their work commitments in order to undertake hepatitis C treatment because people cannot do without their pharmacotherapy. Compounding this is the fact that places on public programs where no pharmacotherapy fees are charged are few and far between and are generally more restrictive such as providing little or no access to take away doses. Places on public programs are also generally reserved for highly marginalised drug users and therefore unlikely to ever be able to act as a 'respite program' away from paying fees while people undertake hepatitis C treatment. Even if people were able to gain access to a place on a public program, people would be concerned about losing their place on their preferred community program and the risk of not having take away doses restored when they completed hepatitis C treatment. For all of these reasons there is a need to develop a program of pharmacotherapy fee support for people who are undertaking hepatitis C treatment and whose income has been reduced as a result.
- **Poor Access to Pain Relief and Other Medications for Treatment Side-Effects** – the potential of poor access to pain relief and other symptomatic relief for hepatitis C treatment side-effects is acting as a barrier to hepatitis C treatment uptake for people on pharmacotherapies. This issue is important

because the research outlined elsewhere in this paper shows that concerns about side-effects from treatment is repeatedly identified as one of the major reasons why people with a history of injecting drug use are reluctant to commence hepatitis C treatment. Research has shown that people with a long term history of opioid use are not only more sensitive to pain but are likely to require significantly higher levels of pain relief to achieve a comparable level of pain management as people who are opioid-naive (White, 2004). Despite this evidence, it is recognised that people on opioid pharmacotherapies are routinely denied access to pain management and are accused of 'drug seeking' behaviour (Morgan, 2006). It is this general culture of distrust and lack of empathy for people's pain and suffering that is acting as a significant deterrent in relation to hepatitis C treatment. People are genuinely concerned about undertaking hepatitis C treatment in an environment that too often has seemed indifferent, even hostile to their needs.

- **Concerns about Confidentiality** – while the convenience of having your hepatitis C and pharmacotherapy treatment in the one place has appeal for some people in pharmacotherapy treatment, there can also be some potential disadvantages to this combined treatment approach. Although current drug users are eligible to access hepatitis C treatment under the current S100 criteria, such access can effectively be undermined if your only way to get hepatitis C treatment is at your pharmacotherapy service or through your pharmacotherapy prescriber. The changes to the eligibility criteria mean that some people are quite willing to be honest about their drug use with their hepatitis C specialist particularly because people are concerned that withholding such information could adversely affect their hepatitis C treatment. This honesty in the therapeutic relationship can be undermined however if the individual is concerned that their pharmacotherapy provider may have access to their medical records associated with their hepatitis C treatment. This situation can be particularly serious if people are experiencing problems and/or if their circumstances significantly change during hepatitis C treatment. People can be left feeling unable to confide in their hepatitis C treatment team about issues such as housing problems or drug interactions for fear this will be relayed to their pharmacotherapy provider and be seen as signs of illicit drug use or 'instability'. While not all pharmacotherapy services react in the same way to signs of illicit drug use, it is fair to say that people on pharmacotherapies are generally concerned

about how such disclosure could impact on their treatment and in particular on access to take away doses. Some people are also concerned about the potential lack of confidentiality associated with accessing hepatitis C treatment in the pharmacotherapy setting as it effectively tells everyone "I have hepatitis C". Many programs are relatively small and just being seen accessing the hepatitis nurse or hepatitis specialist automatically discloses your status whether you want that person to know or not (Treloar, 2010b).

- **Lack of Knowledge and Expertise on Hepatitis C** – many of the specific issues outlined above can be related back to the fact that hepatitis C, including prevention, monitoring, treatment and management are not sufficient priorities for many opioid pharmacotherapy services. While there are a number of pharmacotherapy services who have begun taking a much greater level of interest and engagement in hepatitis C, particularly those services involved in trialling hepatitis C treatment in the pharmacotherapy setting, there is still a long way to go. Reports from people on pharmacotherapies indicates that hepatitis C is still viewed as 'non-core business' by too many services (Treloar, 2010b). In other instances, people report being provided with incorrect or misleading information in relation to hepatitis C and/or are told they will need to speak with another service or see another practitioner if they want to address their hepatitis C (Peer report). The problem with this situation is that the service is (unintentionally) sending a message to people on pharmacotherapies that hepatitis C is not 'our priority' which can act as a further justification for people to continue deprioritising hepatitis C in their lives. "If the health system doesn't take hepatitis C seriously – why should I?" (Peer report) One of the biggest difficulties for people contemplating hepatitis C treatment can be when to make the decision to start treatment, particularly if people are basically feeling well. Should one start treatment before there is obvious liver damage or could you be one of the 'lucky' ones that may never 'need' treatment? One of the problems that arises if drug treatment services are not sufficiently engaged and informed in relation hepatitis C, is that people do not get the assistance they need to move through this often complex contemplation process. People are not encouraged to maintain regular monitoring of their liver and condition which can be one of the main methods of removing the 'guessing game' and the uncertainty. Anecdotal experiences from pharmacotherapy consumers suggests that rather than engaging people in appropriate hepatitis C monitoring, concerns

about possible hepatitis C related symptoms are too often dismissed without proper investigation and simply put down to “being on methadone” (Peer report). Access to primary health care is poor for people with a history of injecting drug use and for this reason people on pharmacotherapies frequently have very little other contact with the health system. In this context, it is critical that opioid pharmacotherapy providers view hepatitis C as ‘core business’ and establish appropriate partnerships, links and training to support their role in this area. Recent piloting of hepatitis C treatment provision in pharmacotherapy settings is proving to be a useful strategy to promote hepatitis C as ‘core business’ for these services. Providing hepatitis C treatment in all pharmacotherapy settings however is neither feasible nor appropriate and therefore additional strategies to encourage pharmacotherapy services to view hepatitis C as a priority are needed.

- **Lack of Pharmacotherapy Options** – in addition to improving the flexibility and design of the existing opioid pharmacotherapy program, there is also an urgent need to expand the range and type of opioid-based and other pharmacotherapies that are available within the community including heroin prescription and other injectable options. There are many reasons why this development is needed but in the context of hepatitis C, one of the main reasons is that additional pharmacotherapy options would increase the uptake of drug treatment. It is estimated that in relation to opioid pharmacotherapy treatment alone, there is currently at least 40,000 people who are eligible for OPT but who are not currently accessing the program (AIHW, 2009). This is important because while people are not being given access to the substances they want, in a form that meets their needs, people will continue to use illicit drugs (whether they are on the available pharmacotherapies or not) with all of the well-documented health and social issues that this entails. As long as people feel trapped in the illicit drug market and cannot address their needs through the available drug treatment options, it will be difficult if not impossible for many people to get to a place where they can prioritise their health at all, let alone prioritising hepatitis C or hepatitis C treatment.
- **Lack of Peer Support** – as in the other settings above, the general lack of formal peer support in pharmacotherapy settings is also acting as a major barrier to people contemplating and taking up hepatitis C treatment. The “Models of Peer Support” section in earlier in this paper provides ample evidence demonstrating the effectiveness and benefits of hepatitis C treatment peer support in the pharmacotherapy environment in particular. The Healthy Liver Clinic model piloted in Victoria and the ETHOS Project currently underway in NSW are leading the way on demonstrating this effectiveness. There are clear signs of the impact that properly resourced peer support programs can have on treatment engagement, contemplation and uptake. Significantly more work needs to be done to support the further development of peer support in the pharmacotherapy context including resourcing drug user organisations to take a leadership role in this area.

Addressing the Barriers to Hepatitis C Treatment in Pharmacotherapy Settings:

- **Program Policies and Guidelines** – conduct a review of national and jurisdiction guidelines and policies governing the operation and administration of the Opioid Pharmacotherapy Program with the aim of:
 - » removing unintentional barriers to hepatitis C treatment access and uptake;
 - » improving program flexibility and responsiveness for those undertaking hepatitis C treatment;
 - » removing punitive aspects of the program design and approach; and
 - » Improving access to pain management.
- **Cost of Pharmacotherapies** – the Commonwealth and all states and territories (with the exception of the ACT) should undertake a joint process to address the growing problems and unintended consequences associated with the increasing cost of pharmacotherapy dispensing fees including:
 - » Development of a nationally consistent subsidisation scheme (similar to the system in ACT) whereby the cost of pharmacotherapy dispensing is partially subsidised by government with a payment to pharmacies and clinics to partially cover their costs and a set consumer copayment of \$15 per week maximum to cover the balance; and
 - » Development of a temporary program of pharmacotherapy fee support for people who are undertaking hepatitis C treatment and who:

- Have reduced incomes as a result of hepatitis C treatment; or
 - Are living on low incomes; and/or
 - Are struggling to manage the additional health and other costs associated with hepatitis C treatment including the cost of side-effects management medications.
- **Workforce Training & Development** - all clinical and non-clinical staff within pharmacotherapy settings should undertake training on a regular basis in relation to stigma and discrimination and attitudes and values towards people with a history of injecting drug use including removing barriers to accessing pain management.
- **Confidentiality and Informed Consent** – pharmacotherapy services should undertake a review of operational practices to ensure that all policies, procedures and systems are appropriate for maintaining client confidentiality in the context of ‘enhanced’ service delivery such as combined pharmacotherapy and hepatitis C treatment. Specific attention should be paid to questions such as:
 - » when does information about clients need to be shared with other health providers particularly in the context of multidisciplinary teams, shared care arrangements, etc;
 - » how is full and informed client consent assured when information sharing does occur;
 - » the unintended impacts of physically co-locating pharmacotherapy and hepatitis C treatment services; and
 - » understanding the way that conflicts between pharmacotherapy and hepatitis C treatment approaches can create barriers to hepatitis C treatment.
- **Legitimising Hepatitis C as ‘Core Business’ for Pharmacotherapy Services** – development of a national training and ongoing accreditation system for pharmacotherapy services on best practice approaches to hepatitis C prevention, diagnosis, treatment and care. This training needs to focus on building organisational cultures that support and legitimise hepatitis C service delivery as well as developing the skills and expertise of staff in clinical and non-clinical roles.
- **Expanding Pharmacotherapy Options** – the Commonwealth and jurisdictions to work together to develop and implement additional evidence-based pharmacotherapy options as a strategy to increase drug treatment uptake and reduce barriers to hepatitis C treatment and management. These options should include heroin prescription and other injectable opioid and non-opioid pharmacotherapies.
- **Peer Support Models** – in line with findings from piloted and evaluated peer support approaches in pharmacotherapy settings, develop and implement tailored peer support approaches as a fully integrated component of a multi-disciplinary team approach. AIVL believes properly resourced, supported and designed peer support models will significantly reduce a number of the barriers to hepatitis C treatment in the pharmacotherapy setting identified above including:
 - » positively effecting the organisational culture and general environment within the pharmacotherapy service;
 - » challenging negative stereotypes and poor attitudes among clinical and non-clinical staff;
 - » providing more flexible and responsive program approaches and service models;
 - » assisting clients to develop their health literacy in relation to hepatitis C;
 - » supporting clients in their clinical interactions including acting as a ‘translator’ or ‘go-between’ particularly on sensitive issues;
 - » supporting people through the treatment contemplation phase and reducing treatment anxiety;
 - » assisting people to meet their needs and requirements for hepatitis C treatment eligibility particularly on issues that people are unlikely to raise with clinical staff such as financial problems, housing difficulties, ongoing illicit drug use, etc;
 - » assisting people through the hepatitis C treatment process and to adhere to treatment requirements; and
 - » reduce the workload of clinical staff thereby providing more capacity for assessment and treatment management.
- **Peer Support Resourcing** - Peer support for people with a history of injecting drug use in opioid pharmacotherapy settings must be adequately resourced and supported with formal

linkages to the relevant drug users organisation in order to provide appropriate models and adequate supervision and support for peer support workers.

v. The Role of Practice Nurses, CNCs, Nurse Practitioners:

While not a separate treatment environment or model, it is important to make some further brief comments on the growing use of nurse-led and nurse-supported approaches in the area of hepatitis C treatment. The diversity of the people seeking treatment and the complexity of the issues being managed in association with hepatitis C treatment has led many specialists and GPs to engage specialist nurse roles and/or RNs to assist with tasks including:

- Reviewing and supporting patients referred;
- Providing education to patients about treatment;
- Overseeing treatment administration and treatment care;
- Liaising with community based organisations;
- Conducting diagnostic tests;
- Providing ongoing counselling and support for patients;
- Providing support to GPs (re: shared care models); and
- Recruiting new GPs to shared-care models and educating GPs about hepatitis C treatment (Richmond, 2009 and McNally, 2009).

One of the other important developing roles being undertaken by hepatology nurses is that of working collaboratively with peer support workers (in the very limited contexts where they exist) to enhance capacity and provide better access and service delivery in relation to hepatitis C generally and hepatitis C treatment in particular. The enormous potential for peer support to be used together with nurse-based approaches to significantly expand access to and the uptake of hepatitis C service delivery has been explored in the earlier section on "Peer Support Models". Both the Health Liver Clinic pilot project in Victoria and the continuing ETHOS Study in NSW have highlighted the difference it makes for hepatology nurses and peer support workers to operate as members of an integrated, multidisciplinary primary care team rather than viewing peer support as an optional, external referral for the patient's benefit only. The HLC and ETHOS models both highlight the value of fully integrated peer support to the service as well as to the individual clients/patients. In particular, properly supported, trained and resourced peer support workers

have been found to enhance the overall capacity of the service in relation to hepatitis C treatment by simultaneously expanding the role of peer support workers and reducing unsustainable workloads for hepatology nurses in very busy clinical environments. Some of the enhanced activities/roles undertaken by peer support workers have included providing information and education to patients, providing support during the treatment contemplation process, conducting reviews and initial assessments, providing intensive support with psychosocial issues during treatment, assisting with screening and testing, etc.

Although the implementation of this type of enhanced and integrated peer support has only been piloted in a very limited number of settings thus far, it is important to note the growing level of support from hepatology nurses in those settings for the expanded role of the peer support workers. Too often multidisciplinary team approaches to hepatitis C treatment are described as including specialist physicians, GPs, hepatology nurses and allied health services. What this can incorrectly suggest is that if your service or model of care engages a hepatology nurse or practice nurse, then there is no need for peer support workers as information, education and support of patients is undertaken by the CNC or RN. While the linkages and communication between nursing staff and peer support workers is critical, they undertake different roles within the health care setting. Employing a hepatology nurse or other nursing staff has been shown to have a positive impact on the quality hepatitis C treatment services (McNally, 2009). Having said this however, including nurse-led or nurse-based models does not remove the need for hepatitis C treatment services to also invest in peer support approaches. Both sets of skills and expertise are needed when delivering a complex form of treatment among a patient population that includes many people who are marginalised and social isolated.

d. Other Issues in the Treatment and Management of Hepatitis C:

In addition to the main barriers to hepatitis C treatment service delivery outlined above, there are a range of other clinical and non-clinical factors that can impact on an individual's decision to undertake hepatitis C treatment and/or their capacity to engage in the management of their chronic hepatitis C infection. Given their potential impact particularly for people with a history of injecting drug use it is necessary to very briefly identify these factors and strategies for addressing them.

i. Housing

Understandably, being in stable housing is one of the social factors that service providers consider an important part of the assessment and decision making process in relation to eligibility/sustainability for hepatitis C treatment. For people with a recent history of injecting drug use, securing a stable and suitable housing environment for hepatitis C treatment may be an area that requires more intensive support and advocacy. If we are aiming to increase access to and uptake of hepatitis C treatment among people who may be currently injecting and/or on opioid pharmacotherapies, providing confidential and sensitive support on issues such as housing stability and suitability will need to become a much greater focus for the majority of services. While homelessness may be a factor for some people, many more people will be affected by less obvious housing stability and suitability problems. Financial problems associated with illicit drug-related poverty and/or the increasing cost of opioid pharmacotherapy fees can result in people losing their housing or not being in a position to secure a stable long-term arrangement in their housing due to owing or having a history of owing rent in arrears. This situation can often result in people having to 'take what they can get', being forced to accept less-than-stable very short term, month-by-month rental properties, etc. People with a history of injecting drug use are extremely vulnerable in an increasingly over-saturated rental housing market. Having said that however, government housing arrangements can also bring their own share of difficulties and stress.

Having relatively 'stable' housing however does not mean that your housing is necessarily 'suitable' for undertaking many months of a complex and serious treatment. Vulnerability in one's financial and housing situation can lead to people being forced to live with poor, dysfunctional or non-existent facilities and amenities such as sub-standard plumbing, little or no natural light or ventilation, infestations, old and unsanitary conditions, having to share poorly maintained amenities, living surrounded by ongoing violence, the stress associated with high levels of ongoing AOD use, etc. These are significant issues for people contemplating and/or undergoing a treatment that can have serious side-effects particularly in terms of mental health. For people engaged in active drug use, their housing situation can also change considerably over the course of a 6-12 month period whereby their hepatitis C treatment may begin with a stable housing arrangement but may be eroded before they have completed treatment. Not surprisingly people rarely wish to disclose these situations to their treating physicians and even hepatology nurses due to the shame and fear of judgment associated with

such issues. When stable housing is a requirement for commencing hepatitis C treatment, people will be extremely reluctant to tell their clinical team about housing problems. Instead, people will simply try to cope on their own. This too often results in people being seen as being deceptive or less than honest when in fact they feel optionless.

The available evaluations and initial findings from pilot projects however show that peer support is one of the best ways to address some of these complex and sensitive issues for people with a history of injecting drug use. With hepatitis C treatment increasingly being provided in the context of pharmacotherapy programs, people may become more rather than less reluctant to disclose their housing stability and/or suitability issues. The main reason will be concerns about losing access to take away doses, fear of increased monitoring such as urine testing and other punitive measures if people are seen as "unstable". Such issues almost always require significant advocacy work and liaison between the individual and housing/tenancy services to resolve them – work that most hepatitis C and pharmacotherapy services would not have the capacity to undertake even if the patient was to disclose their circumstances. Trained, supported and resourced peer support workers are specialists in such issues and in the advocacy and liaison involved. While AIVL does not wish to see problems associated with housing used as a reason to deny access to hepatitis C treatment for people with a history of injecting drug use, we are concerned that people will be self-assessing their situation as unsuitable or needlessly compromising their one chance at funded hepatitis C treatment, simply because we have not addressed the reality and complexity of people's housing issues sufficiently. In this context, it is critical that peer support approaches, run by and for people with a history of injecting drug use, become a standard aspect of best practice hepatitis C treatment service delivery. Peer support workers are the ones with the trust, credibility, understanding, time and expertise to manage issues such as housing problems within a multidisciplinary team approach.

Addressing Housing Barriers:

- There is a need for peer-driven social research to gain a better understanding of housing issues for people with a history of injecting drug use;
- Increased resourcing needs to be made available to allow hepatitis C services to engage peer support workers to assist and support people on or contemplating hepatitis C treatment with housing issues.

ii. Home Care Support

Another area of need and support in relation to increasing access to and uptake of hepatitis C treatment is that of home care support during treatment. Many people with hepatitis C and a history of injecting drug use do not have family or social networks upon which they can rely and/or their family or social networks are not aware of their drug use history and/or hepatitis C status. This situation can act as a barrier to people making the decision to commence hepatitis C treatment or can risk people not completing a course of treatment due to fear of, or not being able to look after oneself in an independent manner at home when ill. The same situation can lead to people already on hepatitis C treatment ceasing treatment early due to being unable to cope on their own. Others, particularly people who are actively using or living on very low incomes may need assistance with being able to afford healthier food during treatment particularly if type II diabetes and/or fatty liver syndrome are complicating factors.

The Community Support Network (CSN) is a long-standing project of the AIDS Council of NSW for people living with HIV/AIDS. The program operates with a staff team and a pool of volunteers who provide in-home support for PLWHA who are too unwell to manage all of their home care needs on their own or those who may need more short-term support and assistance. To be eligible for home-based care, clients need a diagnosis of physical or cognitive impairment as a result of, or in the presence of, HIV infection resulting in impaired capacity for independent living (ACON website). AIVL believes a peer-based CSN-type program for people with hepatitis C and a history of injecting drug use is overdue. With adequate resourcing and support we believe it would be possible to build a national network of home care support programs for people in our community who are undergoing hepatitis C treatment and are unable to independently manage their own home care during that time. The programs would need resourcing for a core staff team who could then train and coordinate a pool of peer-based volunteers who would provide assistance in the community for 2-5 hours per week. The service offered by the program would include assistance with:

- Shopping;
- Cooking;
- Cleaning
- Transport to appointments, pharmacotherapy dosing, etc.

The home care support programs would operate from peer-based drug user organisations with formal

linkages with hepatitis C peer support workers in the various clinical settings. In this way, people needing support from the program could be referred by peer support workers, hepatology nurses and clinicians in the hepatitis C treatment services and in the reverse, the home care support programs could refer people to the peer support workers and services for care and support issues outside of the home care program. With The National Hepatitis C Strategy 2010-2013 aiming to significantly increase the numbers of people accessing treatment for hepatitis C over the next few years, there needs to be concurrent investment and planning in support services to ensure the quality of care and the dignity and respect of those undergoing treatment.

Addressing Barriers Associated with the Current Lack of Home Care Support:

- Funding needs to be provided for a national needs assessment and social research project on home care support needs for people on hepatitis C treatment;
- Funding needs to be provided to establish a series of peer-based home care support pilot projects with evaluation with the aim of developing best practice hepatitis C home care support models.

iii. Centrelink & Income Support

Many people experience problems associated with meeting their Centrelink requirements when on hepatitis C treatment (based on verbal reports from hepatitis C peer support workers). One of the reasons for this is because people often have numerous medical, health and social appointments when on hepatitis C treatment and/or because people are also feeling unwell due to treatment side effects. For people who also have a history of injecting drug use they are frequently also dealing with daily appointments associated with being on opioid pharmacotherapies and may be managing other acute and chronic health problems. If people are also dealing with legal issues or obligations associated with the criminal justice system such as probation or parole requirements or family court issues this can make it very difficult to meet job capacity assessment obligations under Centrelink. Juggling large amounts of appointments across many of the issues outlined above is not unusual particularly for people who are attempting to 'get their life together' perhaps after time in prison or once on drug treatment.

As it currently stands, there are mechanisms within the Centrelink structure to provide income support and flexibility to people with a chronic illness or disability. Hepatitis C peer support workers have reported successfully advocating for people on

hepatitis C treatment to access Newstart Allowance (Incapacitated), Sickness Allowance and even Disability Support Pensions depending on their individual needs and circumstances. While it is appropriate that the system has been responsive to the needs of these individuals, hepatitis C peer support workers also state that there are problems with what appears to be the 'ad hoc' nature of the current approach. Although peer support workers and other support staff in hepatitis C treatment services have been able to successfully advocate for people there are concerns that the outcomes in such advocacy cases seem to rely too heavily on the individual Centrelink officer involved rather than a consistent policy approach.

It is absolutely essential that people do not have the stress and anxiety of their benefits being suspended for 8 weeks or more and/or losing their income entirely during hepatitis C treatment because they do not fulfill Centrelink activity requirements. For some people, especially those experiencing complications and side effects, it could result in a complete and premature withdrawal from hepatitis C treatment and all the consequences of that decision. Although hepatitis C peer support workers are undertaking successful advocacy with Centrelink for people on hepatitis C treatment, there are only a small handful of such peer support workers in the country. While this remains the case and people are left at the mercy of ad hoc decision making, the current Centrelink approach to income support will be acting as a barrier to hepatitis C treatment for many.

Addressing Barriers Associated with Centrelink and Income Support:

- There is a need to undertake social research to gain a better understanding of the impact of current Centrelink requirements on people during hepatitis C treatment and to recommend strategies to address any issues identified;
- There is also a need for increased resourcing to allow hepatitis C services to engage peer support workers to assist with Centrelink and other income support issues for people contemplating, undergoing and post hepatitis C treatment.

iv. Post Hepatitis C Treatment Support

One of the most neglected areas of the hepatitis C treatment experience and people's support needs is what happens to people in the immediate post-treatment stage. This is reflected by the fact that there are very few formal studies that have looked at the post hepatitis C treatment experience, in both physical and psychological terms. One such study, *Recovery*

from hepatitis C treatments interviewed 27 people about their experience post treatment. While this is a relatively small sample, even a brief trawl of hepatitis C blogs and forums indicate that the experiences detailed in the study are commonplace, with many people relating ongoing physical and psychological side effects many months after treatment has finished. The following are some salient points from the study that highlight the key common themes for people post hepatitis C treatment.:

- *Of the 27 participants in this study, 25 reported persistent physical and psychological side effects/symptoms after completing hepatitis C treatment;*
- *11 participants said that their symptoms had lasted for up to one year after treatment had finished and 14 participants said that their symptoms had lasted for more than one year after treatment;*
- *Informed consent procedures did not address the post-treatment period and participants were not forewarned of the possibility of ongoing side effects after treatment. Similarly, participants said they were given unrealistic expectations about increased energy and improved quality of life from clearing infection;*
- *The end of treatment was a time when participants' demand for information was high;*
- *The clinic environment often intimidated participants and was a barrier to them seeking post-treatment information and medical care regarding persistent health problems;*
- *Specialist physicians rejected an association between the treatment regimen and participants' accounts of persistent side effects/symptoms;*
- *Participants' difficulties with emotions, strained relationships and trouble in coming to terms with non-response were exacerbated by a lack of post-treatment information, advice, referrals, support and medical care to address ongoing symptoms (Hopwood, 2009).*

While some people post treatment felt "a real zest for life" and commented that they "feel a real difference", others were not so positive in attitude:

"The side effects do last for a considerable time after... I was still feeling unwell up until about three months. I would say even longer for the aches and pains in my joints."

"It is after this treatment I am actually impotent. One hundred percent impotent."

"I thought I was going to clear! I really did... and my drug use and ill health and all that was going to be a memory. And I cannot begin to tell you what a dream that was for me" (Hopwood, 2009).

This is not to suggest that most people have a negative experience of treatment and the post-treatment period, but to indicate that at least some people do. The NCHSR paper makes a series of recommendations, one of which was:

"...either the development of a more efficacious and tolerable treatment is required, or significantly more resources need to be allocated toward increasing the range of supports and health care services that are available to people during and after treatment for hepatitis C infection before more people with hepatitis C can be expected to consider treatment" (Hopwood, 2009).

There appears to be a paucity of formal information/support materials for people who have completed hepatitis C treatment. *The Hep C Review*, a publication of Hepatitis NSW, recently published an article detailing the lingering side effects that many people experience post treatment. This article also calls for more formal avenues of post treatment support and refers to the paper by Hopwood cited above (Rigg, 2009). In 2002 the then Australian Hepatitis Council produced a resource entitled *moving on after treatment* (Australian Hepatitis Council, 2002). This was updated in 2010 with a new resource called *Hepatitis C; Treat it, Beat it* which contains some information on post-treatment issues and where people can get more information and/or support (Hepatitis Australia, 2010). AIVL too has very recently produced a new resource, *C Through*, a hepatitis treatment diary that includes some information on what people can expect post treatment and how they can find support during this period. The AIVL resource is specifically written for people with a history of injecting drug use and the issues that may be important for them (AIVL, 2010a). This resource builds on the stories and experiences initially documented in *It's a Viral Life – personal stories from people with hepatitis C* which is a CD-rom resource produced by AIVL in 2008 (AIVL, 2008a). In addition, AIVL has recently launched a new online peer support social networking site *Our C-ciety* which provides peer support and information for people who have a history of injecting drug use following hepatitis C treatment. *Our C-ciety* can be accessed via the main AIVL website.

Despite the available information however, one of the main problems is that post treatment information and support does not appear to be being taken seriously enough by many hepatitis C treatment services. As models of hepatitis C treatment are diversified and the pressure to increase the numbers of people treated intensifies, it will be less and less likely that people will get access to the post treatment information and support they need. GP Shared Care arrangements can mean that people have relatively little contact with their treating specialist and if they are also under the care of a busy GP who does not bulk bill, it is very easy to envisage people being estranged from the health system at the time when their information and support needs are at their highest. It is critical that people are adequately supported to complete their treatment journey and depending on the outcome, supported to understand the options and challenges that lie ahead. The following quote from a person who completed treatment under a shared care arrangement highlights what can happen in the post treatment period:

"I only saw my liver specialist a couple of times and felt pretty intimidated in the hospital environment anyway so that suited me. I had a pretty good GP looking after me for most of the treatment and while I was on treatment he was good. But he is a really busy doctor and it can be hard to get an appointment with him. As soon as the drugs stopped, I mean the day they stopped I felt like I was completely on my own. No-one, not the liver specialist or the nurse from hospital clinic or the GP contacted me to tell me what should happen from that point. I was terrified of finding out it didn't work so I wasn't rushing to contact them either. I felt really alone and ended up over 12 months later taking myself to my methadone prescriber to get some blood tests done to see if I cleared. I did, but I don't think I should have been left on my own to deal with all of that."

Post treatment information and support needs to be prioritised by hepatitis C treatment services. In particular, services need trained, supported and resourced peer support workers who can build relationships with people across their treatment journey and ensure that they get the support and information they need in the post treatment period. This is always a highly emotional time for people particularly if the treatment is not successful. Services

need to ensure people have adequate support for managing both physical and psychological post treatment side effects at the clinical and peer support levels.

Addressing Barriers to Post Hepatitis C Treatment

Support:

- Hepatitis C treatment services need to place a much greater priority on addressing post treatment information and support needs;
- There is a need for increased resourcing for hepatitis C peer support for people throughout the hepatitis C treatment journey;
- Further social research into post treatment support needs for people with a history of injecting drug use should be conducted.

v. Self-Management of Chronic Hepatitis C

Although this paper has mainly focused on barriers to accessing mainstream clinical services in relation to hepatitis C, our assessment of care and support needs for people with hepatitis C and a history of injecting drug use would not be complete without some reflection on the role of self-management strategies and the role of complementary and alternative therapies in particular. This is mainly because with so many people either not ready, not willing or not needing to have hepatitis C treatment in the short term, many people are very interested in taking steps to self-manage their hepatitis C and perhaps improve their general liver health. It is also the case that self-management strategies and complementary therapies often appeal to people with a history of injecting drug use, particularly if they have had poor experiences in the mainstream health system.

i Complementary and Alternative Therapies:

Although there are a divergent opinions about the effectiveness of complementary and alternative therapies for hepatitis C and liver health, there is work suggesting that a variety of alternative and complementary therapies may assist to reduce hepatitis C-related symptoms, reduce the number and severity of hepatitis C treatment side effects and can help to achieve and maintain good general health. The modalities suggested include massage, naturopathy, homoeopathy, traditional Chinese medicine, acupuncture, meditation and physical therapies/ activities such as Tai Chi and Qigong (Salmond, 2009a). In addition, there are many other complementary and alternative therapies available besides those mentioned above.

Research also suggests that meditation “has the potential to ameliorate the physical and psychological symptoms of chronic illness, as well as serve as a primary, secondary and tertiary preventive health strategy.” In addition, meditation skills “can be useful at every stage of the disease and have been shown to have an impact on both the physical and psychological components of chronic disease states.” Meditation has the capacity to increase an individual’s resilience and coping skills, as well as providing the individual with broader choices and the ability to “choose options outside the habitual and conditioned emotional and mental responses and thought patterns most of us rely on” (Koerbel and Zucker, 2007).

Hepatitis C an Expanding Perspective, contains a chapter that provides an overview of the key benefits of complementary and alternative therapies, as well as sounding a number of warnings in the use of some products. Some conclusions and key messages include:

- *Approximately 35% of patients in liver clinics are taking complementary and alternative medicines to manage their symptoms;*
- *There is some good quality evidence that herbal medicines and/or vitamins can reduce liver inflammation (ALT) and may improve quality of life in individuals with chronic HCV infection;*
- *There appear to be safe and effective treatments that can be taken concurrently with antiviral therapy... (Salmond and Bensoussan, 2009).*

In the same text, Richmond writes that “Complementary and alternative medicine (CAM) practitioners are not officially acknowledged as members of the hepatitis C health care team”, although “the holistic philosophy underpinning CAM practitioners’ approach to health is appealing to many people with chronic hepatitis C because it is often more sensitive to their needs than conventional medicine”. With respect to stigma and discrimination, “CAM practitioners have been found to hold more compassionate and positive attitudes towards people with hepatitis C and people who inject drugs” and “CAM practitioners may provide a refuge for people who have experienced discrimination or judgemental care in the conventional health system” (Richmond, 2009).

ii Alcohol Use:

The effects of alcohol on hepatitis C-related liver damage and disease progression have been well documented in the available literature. A 2004 article titled *Hepatitis C and Alcohol*, makes the following points with regards to the affect of alcohol consumption on hepatitis C disease progression and treatment:

- *Excessive alcohol consumption among patients infected with chronic hepatitis C is likely to result in more severe liver injury, promoting cirrhosis and increasing the risk for development of liver cancer*
- *...heavy drinking during antiviral (interferon) treatment has been shown to impede patients' responses to therapy. Abstaining from drinking before and during treatment improves patients' responses to antiviral therapy (Schiff and Ozden, 2004).*
- *Alcohol interferes with IFN's antiviral action, affecting the rate of HCV replication, the clearance of HCV, or both.*
- *All patients should be educated regarding the effects of alcohol on the course of HCV.*
- *Patients with an understanding of the relationship between HCV and alcohol use may be increasingly motivated to make and sustain healthy lifestyle changes (Silderbogen, 2009).*

In addition, the following passage summarises the issues around hepatitis C treatment and alcohol use:

The evidence is strong that continued heavy alcohol intake during interferon treatment adversely affects treatment effectiveness. Further, depression, irritability, and anxiety – side effects that occur in 20 to 30 percent of patients who receive interferon treatment – may be especially difficult to manage for patients with a history of alcoholism, predisposing them to drinking again. Despite this risk, the data do not support withholding interferon therapy for chronic HCV from patients with a history of alcoholism or heavy drinking if they remain abstinent and have adequate psychosocial support during treatment. Likewise, light-to-moderate drinkers should not be excluded from HCV treatment, nor should a period of abstinence before starting therapy be enforced in this patient population (Schiff and Ozden, 2004).

An article from a 2003 newsletter produced by www.hcvadvocate.org states that “recent studies in Japan, Italy and the United States have shown that a period of abstinence from alcohol for three or more months before commencing interferon therapy significantly improves the patient’s response to therapy” (Highlyman, 2003).

Psychosocial Issues and Mental Health Treatment Recommendations for Patients With Hepatitis C (2009) states that “reduction in alcohol use is one of the most important behavioural changes patients can make to slow the rate of HCV progression.” The article also raises the following points:

- *Active drinking accelerates HCV-related liver damage and decreases effectiveness of IFN therapy.*

Despite the clear messages from the available evidence, it is important to recognise that for some people with a history of injecting drug use there can be a range of highly complex issues surrounding alcohol intake and reduction. People with a history of injecting drug use frequently report that increased alcohol intake when they are attempting to reduce or maintain abstinence from illicit drug use (Peer report). In this regard, hepatitis C services need to be aware of the serious implications of creating an expectation of a reduction or abstinence from alcohol use among clients with a history of injecting drug use. While it should be noted that alcohol use is not an issue for all people with hepatitis C and a history of injecting drug use, it is a serious issue for some and for this reason needs to be handled with a great deal of care. In particular alcohol reduction or abstinence should not be used as a basis for excluding people from access to hepatitis C treatment and any decision to reduce or abstain from alcohol use must be a voluntary one by the individual client.

Further, if services are recommending reductions or abstinence from alcohol use for people with a history of injecting drug use, those services also have a responsibility to ensure they have, or have ready access to, expertise on managing drug and alcohol issues and provide non-judgemental care and support for clients. Services should not under-estimate the potential for unintended negative consequences if people are forced or feel forced to reduce or abstain from alcohol use at a time when they are commencing or undertaking a physically and psychologically difficult form of treatment. People with a recent history of injecting drug use in particular may need intensive support to weigh the pros and cons of reducing or eliminating alcohol use before or during hepatitis C treatment. AIVL recommends this support be provided through properly trained, supported and resourced peer support workers who are part of integrated multidisciplinary teams. Such peer support workers can assist people to consider practical and realistic self-management strategies in relation to their alcohol intake as well as ensure informed consent in relation to alcohol use and hepatitis C treatment.

iii Smoking:

Psychosocial Issues and Mental Health Treatment Recommendations for Patients With Hepatitis C (2009) includes a brief section on smoking and HCV, making the following points:

- *Smoking may lead to more rapid progression of HCV infection, including hepatic fibrosis.*
- *...smokers may also have a lower response rate to IFN therapy.*
- *...not only does cigarette-smoking negatively affect liver function, risk for liver cancer, and overall health, but it has also been associated with reduced quality of life in HCV-positive patients* (Silderbogen, 2009).

Although AIVL recognises the above evidence and the general health benefits of smoking cessation, for the same general reasons as identified in relation to alcohol use above, discussing smoking cessation with clients who have a history of injecting drug use needs to be managed carefully. In discussions with peers for this paper, many people stated that giving up smoking was something they could not contemplate. This is supported by research which has highlighted that levels of smoking among people with a history of injecting drug use are extremely high (Scollo and Winstanley, 2008). Peers routinely stated that while they had engaged in many attempts to stop smoking, the mental health benefits they gained from smoking made it extremely difficult for many to maintain ongoing abstinence (Peer report).

It is very important that hepatitis C services understand the link between mental health and smoking for many people with a history of injecting drug use particularly due to the potential psychological impact of hepatitis C treatment. In this regard, any undue pressure to cease smoking in order to access hepatitis C treatment, will act as a major barrier to treatment for many people with a history of injecting drug use. Credible and non-judgemental information and support to assist people to understand the potential impact of smoking on their hepatitis C progression and ongoing liver health could however provide the right environment for people to consider smoking cessation as a self-management strategy. For many people, issues such as smoking cessation (and alcohol and other drug use) is about a personal journey over a long period of time. Supporting people through such journeys is best suited to hepatitis C peer support workers rather than time and resource-limited hepatitis C clinicians. As we have discussed earlier in this paper, the impact of stigma, discrimination and systemic barriers also means that peer support workers are more likely to empathise and gain the trust of clients on these complex issues.

The appeal of self-management strategies including diet, exercise, smoking cessation, alcohol reduction or cessation, mental health, as well as complementary therapies for so many people with hepatitis C makes it an important for hepatitis C services to take seriously. This includes ensuring accurate, credible and up-to-date information and accessible programs are available for those interested in engaging in such approaches. It is also potentially a way for hepatitis C services to engage with people who may feel intimidated by the broader health system and by hepatitis C treatment in particular but who may be willing to discuss issues and strategies they can self-manage. If we hope to make hepatitis C services more accessible for people with a history of injecting drug use, we must be willing to move beyond clinical pathways alone and provide people with avenues through which they can become an active participant in their own health and wellbeing.

Addressing Barriers to Self-Management of Chronic Hepatitis C:

- There is a need to undertake peer-driven social research on hepatitis C self-management information and support needs for people with a history of injecting drug use;
- There is a need for increased resourcing for peer support to assist people to develop effective and relevant chronic hepatitis C self-management strategies;
- Hepatitis C services need increased training in alcohol and other drug issues. ■

5 Conclusion

AIVL believes this paper is essential reading for people across the entire hepatitis C partnership approach. It is ambitious and attempts for the first time to articulate in some detail what it is like to experience the health system as a person with hepatitis C and a history of injecting drug use. Indeed much of the detail and expansiveness in this paper is due to our desire to provide a document that is about more than structures, systems and approaches but importantly, how those mechanisms impact on the lives of people affected by hepatitis C. We believe this paper stands apart from other 'models of care' documents in that it brings the voice and experience of people directly affected by hepatitis C from the margins to the centre. The illegality and process of criminalisation associated with injecting illicit drugs pushes people underground and away from services, family, friends and support. For this reason, it is essential that organisations such as AIVL raise awareness among service providers, policy makers, researchers and others of the experiences of people who have been marginalised and excluded due to their involvement in injecting drug use.

This paper calls for change at the macro and micro levels in relation to hepatitis C prevention, diagnosis, treatment and care for people with a history of injecting drug use. We have provided concrete recommendations in each of the sections above on how we can commence the process of creating a response to hepatitis C that is appropriate and acceptable to those who are living with the condition. These recommendations from across the paper are collected in the next section for ease of reference and to encourage action. As stated above, AIVL acknowledges the important and high quality services and work that are already underway in relation to hepatitis C. This paper does not seek to deny this work, in fact we hope we have highlighted areas good practice as appropriate. But areas of good practice do not mean that we have thought enough, done enough, to secure a foundation for our response to hepatitis C that ensures that even the most marginalised can get access to services and care they need when and how they need it. This is the fundamental challenge this paper has

sought to address. We hope it has achieved this purpose and leads to a complete review of the current approach to hepatitis C among people with a history of injecting drug use. ■

6 Summary of Recommendations

1. Models of Access and Service Delivery:

Principles to underpin hepatitis C models of access and service delivery for people with a history of injecting drug use:

- **Utilising empowerment-based and person-centred approaches;**
- **Building capacity for self-management and self-care – supporting people to manage their own health and conditions;**
- **Ensuring coordinated and integrated care – particularly across specialist, mainstream and community-based services and across the prevention/care continuum;**
- **Valuing effective communication - between service providers and between service providers and clients;**
- **Applying evidence-based policy frameworks, clinical care and management models;**
- **Adopting multi and inter-disciplinary team approaches to the provision of services and care;**
- **Including peer support as a fundamental component of integrated care models;**
- **Ensuring a properly resourced, trained and supported health and allied care workforce including the peer workforce;**
- **Supporting good health outcomes through safe and effective health information management systems; and**
- **Responding to the social and structural determinants of health as part of developing comprehensive models of access and service delivery – including the impact of criminalisation, stigma and discrimination on health outcomes.**

2. Addressing Systemic Barriers to Access and Service Delivery:

i. Recommendations to Enshrine a Human Rights Framework:

Embedding a human rights based approach to access and service delivery for people with chronic hepatitis C would include as a minimum:

- **ensuring privacy protections and confidentiality in service provision;**
- **facilitating access to high quality, non-judgmental, client-focused health services;**
- **eliminating punitive drug treatment approaches and expanding current drug treatment options including injectable pharmacotherapies;**
- **developing legislative mechanisms to ensure the systematic review of existing and new legislation and policies for consistency with human rights principles.**
- **protecting the health and rights of people with a history of injecting drug use particularly in the health, social welfare and criminal justice systems;**
- **encouraging and supporting people with a history of injecting drug use to assert their basic human rights and to lodge complaints against those who violate those rights;**
- **conducting education and empowerment work with people with a history of injecting drug use to challenge the discourses created through structural, cultural and symbolic violence;**
- **conducting anti-discrimination and human rights focused education campaigns targeting the general community, government departments and health and social services;**
- **empowering people with hepatitis C and a history of injecting drug use to undertake self-advocacy and provide peer-based education and support; and**

- ensuring the Australian Government's Social Inclusion Agenda incorporates strategies to tackle the origins and impact of social exclusion on the health and wellbeing of people with a history of injecting drug use.

ii. Recommendations for Harmonising Drug Control Laws with Public Health Approaches:

To ensure a comprehensive and progressive model of reform AIVL recommends:

- **Continuing the development and implementation of diversionary schemes including an increasing focus on:**
 - » Innovative strategies to divert people away from the criminal justice system and reduce reimprisonment rates rather than largely focusing on the opportunistic diversion of people into compulsory, abstinence-based drug treatment – this may include greater use of opioid pharmacotherapy in the community, voluntary community-based support and development programs, etc;
 - » Exploring justice reinvestment as a way to create alternatives to incarceration for highly marginalised people with a history of injecting drug use – that is using resources that are currently allocated to incarcerating people to be 'reinvested' in strategies to keep people with drug related offences out of prison;
 - » Addressing the barriers to accessing diversionary schemes - particularly for Indigenous IDU, people in regional and rural communities and those convicted of certain classes of offences including offences that are classified as violent and people with convictions for violent offences in the past.
- **Expanding the use of decriminalisation beyond simple cannabis offences to include:**
 - » Decriminalising the purchase and possession of small amounts of all currently illicit substances for personal use - up to 10 days supply assessed on individual levels of use and circumstances;
 - » Developing a system of civil penalties for small-scale supply of all currently illicit substances when the supplier is a user of and/or dependent on the substance supplied.
- **Exploring the potential for replacing the current drug control laws with a new system of legal regulation including:**
 - » Undertake the necessary reform to expand pharmacotherapy treatment options to include the implementation of heroin prescription programs through the existing community prescriber and pharmacy dosing model utilised for methadone and buprenorphine – needs to take into account of the models and the lessons learnt from heroin prescription trials and programs in other countries including the factors that ensure such programs are accessible and attractive to the client group;
 - » Commissioning research to provide the evidence base and 'blueprint' for a gradual process of legislative reform to result in a new regulatory system for the availability of all currently illicit substances;
 - » Undertake an independent audit of the 'net harm' caused by current drug control laws, policies and approaches – should include a specific focus on the net effect of law enforcement and interdiction on the health and wellbeing of people with a history of injecting drug use.

3. Addressing Environmental Barriers to Access and Service Delivery:

i. Addressing Barriers to Hepatitis C Primary Prevention Services:

To address the barriers to hepatitis C primary prevention services for people with chronic hepatitis C and a history of injecting drug use AIVL recommends:

- **Improving access to primary health care services for people with a history of injecting drug use** – there are opportunities presented by the current health system reforms particularly through the development of the primary health care organisations (PHCOs) and Medicare Locals (MLs) to increase access to primary health care for IDU. This should involve the development of culturally appropriate services, services for highly marginalised groups of drug users and better access to general primary health care for the broader population of people with a history of injecting drug use. New service models need to

be developed that include multidisciplinary team approaches and peer education and support as core components of any model in the delivery of primary health care for people with a history of injecting drug use.

- **Increasing access to new injecting equipment through NSP particularly peer-based NSP** – there will be opportunities within the national health reform process to improve NSP service delivery. While it is not yet clear where NSP services will ‘sit’ within the new system, AIVL believes there are opportunities to expand access to NSP through purchasing arrangements at the state/territory level through the new LHNs and PHCO/MLs. Alternatively, if responsibility for NSP was shifted to the federal level through the new National Preventative Health Agency, AIVL believes this would require the development of key indicators to support increased resourcing and commitment for a national NSP infrastructure. The benefits of this approach is that it would secure a nationally consistent level of access and service delivery but achieving this would also require the agreement of a set national NSP standards. AIVL would be concerned that such standards would need to operate at ‘best practice’ not ‘minimum’ standards. Whether funding and policy responsibility for NSP remains at the state/territory level or shifts to the Commonwealth, there is now a wealth of evidence supporting the need for existing NSP services to be increased in capacity, number and scope. In particular AIVL would recommend the need to expand access to peer-based NSP services through the expansion of existing peer-based NSPs and through the establishment of new peer-based services. New arrangements under the health reform process will create the opportunity and resourcing for this to occur particularly by adding peer-based NSP to the service mix in the LHNs and MLs.
- **Review of legal, policy and structural barriers to NSP and injecting equipment access** – each jurisdiction should undertake a full review of the relevant legislation, policies and regulations governing the operation of NSP (and other hepatitis C prevention services) to ensure barriers to access are removed. This would include an all of government approach to ensure that issues such as drug control and public health legislation, mandatory reporting, local council regulations, policing practices and environmental planning are all taken into consideration. These issues will also need to be considered in light of the above health system reforms.
- **Peer distribution of injecting equipment** – as part of the above review, priority should be given to undertaking the necessary reforms to allow peer distribution of injecting equipment. Further detail and specific recommendations on peer distribution of injecting equipment can be found in AIVL’s recently published discussion paper *Legislative and Policy Barriers to NSP and Injecting Equipment Access* available on the AIVL website.
- **NSP in prisons** – once again, although this issue would also need to be considered as part of a comprehensive review of legal, policy and structural barriers to NSP access, the urgency of this reform measure in relation to public health and human rights warranted a stand-alone recommendation. Further detail on models and approaches and specific recommendations can be found in AIVL’s *NEP in Prisons* discussion paper on the AIVL website. The need for jurisdictions to seek opportunities to trial NSP in prisons is also addressed in *The National Hepatitis C Strategy 2010-2013*.
- **Workforce training and support** – ongoing and mandatory training for all NSP staff in addressing stigma and discrimination and poor attitudes towards people with a history of injecting drug use should be a standard inclusion in all service delivery models.
- **Promotion and advertising of NSP services** – strategies need to be implemented to improve access to information about the locations, operating hours and services of NSPs and other BBV prevention services within the general community.
- **Increased IDU peer education** – improved access to peer-based prevention education in relation to hepatitis C to address myths and misinformation and increase awareness among people with chronic hepatitis C and a history of injecting drug use of the need to have ongoing access to well-targeted primary prevention services.
- **Hepatitis C Prevention in AOD Settings** – there is a need to provide access to up to date information on BBV prevention and related issues for people with chronic hepatitis C infection who are on opioid pharmacotherapies. Strategies need to be developed to provide access to this information without individuals being forced to disclose current injecting drug use. This could include printed and audio/visual information available in waiting areas, use of peer support workers, peer support groups, internet access

points, availability of drug user magazines and resources, public information sessions and readily available referral information. Ultimately there needs to be policy change to remove the punitive aspects of opioid pharmacotherapy and other AOD treatment approaches. Over time, if people found they did not experience negative outcomes and punishment associated with discussing current injecting drug use in the AOD treatment context, then they may be more willing to access BBV prevention and harm reduction in this environment.

ii. Addressing Barriers to Hepatitis C Testing & Diagnosis Services:

To address the barriers to hepatitis C testing and diagnosis for people with chronic hepatitis C and a history of injecting drug use AIVL recommends:

- **Improving access to education and information on hepatitis C testing and diagnosis for people with a history of injecting drug use** – there needs to be improved peer-based and community education to increase understanding about the need for confirmatory testing and the value of ongoing monitoring for people who are found to be HCV antibody positive. Such education could also support a greater understanding among people with hepatitis C of the testing process including the importance of pre and post-test discussion, the right to informed consent, etc.
- **Ensuring the implementation of the National Hepatitis C Testing Policy** – AIVL recommends the need for a review and development of a strategic communications plan to support effective implementation of the best practice standards within the National Hepatitis C Testing Policy including confidentiality, test discussion, informed consent and quality referral and support. This work should be led by the national advisory structures of the Blood Borne Viruses & STIs Sub-Committee of APHDPC and the Ministerial Advisory Committee on BBVs & STIs or their equivalents. This process will also need to be undertaken in partnership with relevant professional bodies and organisations including the RACGP, ALA, GESA, ASHM, NRL, etc.
- **Workforce training and support to address attitudes and values towards injecting drug use/users** – support and resourcing for the development and implementation of a national ongoing workforce training project aimed at addressing stigma, discrimination and poor attitudes towards people with a history of injecting drug use among health professionals involved in hepatitis C testing and diagnosis. The training would be designed to increase understanding among health professionals of the issues and needs of people with a history of injecting drug use in the hepatitis C testing environment. For this reason, the training should be developed and delivered by AIVL and its member organisations and provide a unique opportunity for health professionals to engage with members of the client group outside of the clinical setting. The training project should be conducted with partnership support from the relevant professional bodies in the hepatitis C testing and diagnosis service delivery environment.
- **Increasing access to peer support in the hepatitis C testing and diagnosis setting** – as research has demonstrated the positive impact that trained peer support workers can have on the willingness of people with a history of injecting drug use to undertake hepatitis C testing and diagnosis, opportunities for peer support in this context should be expanded. Available evidence from evaluations of previous hepatitis C peer support projects could provide suitable models and approaches. Support and resourcing to develop, pilot and evaluate new peer support models in this context should also be included. By ‘peer support’ AIVL means approaches developed and implemented by people with a history of injecting drug use who are affected by hepatitis C. Where pharmacotherapy treatment is a relevant factor, peer support workers should be people with current or past experience of pharmacotherapy treatment. Using trained and experienced IDU peers can assist in reducing fears of discrimination and creating a safe and comfortable testing environment for clients. It can also improve the quality of pre and post-test discussion and informed consent and can facilitate discussions on injecting drug use between physician and patient.
- **Improving access to specialist phlebotomy services and supervised self-collection of venous samples for people with a history of injecting drug use** - specialist phlebotomy services could be provided either through

additional training, support and resourcing for existing pathology services and/or through specialist peers trained in venapuncture who could operate in a variety of primary health care settings (see recommendation to increase access to primary health care in the section on 'Access to HCV Primary Prevention Services' above). In addition to the above, AIVL recommends the development of policies and procedures to allow for greater supervised self-collection of venous samples among people who have a history of injecting use particularly those with few obvious accessible veins. This could be achieved through pilot initiatives in a range of hepatitis C testing settings with appropriate evaluation to allow for the development of best practice models and undertake appropriate risk assessment. AIVL would recommend the incorporation of trained peer support workers into the pilot programs to provide a level of supervision while still ensuring the barriers to testing identified above are removed.

- Removing cost related barriers to hepatitis C testing and diagnosis among people with a history of injecting drug use** – it is recommended that research is conducted into the impact of associated or 'hidden' medical costs on access to ongoing monitoring of hepatitis C and anti-viral hepatitis C treatment assessment. This research should assess the increased health care access needs for people with complex and chronic conditions such as hepatitis C and drug dependency relative to their capacity to pay for such increased care needs. Issues examined should include the impact of increasing consultation fees and concomitant reductions in access to bulk billing in general practice for those who are on limited incomes without healthcare card eligibility. Barriers to hepatitis C monitoring and diagnosis created by the increasing imposition of penalties and fees for missed appointments regardless of income level and the disproportionate impact of routine consultation fees on working people with chronic hepatitis C who are on a pharmacotherapy program with a community prescriber also should be included. The long term implications of illicit drug related poverty on the capacity of people with a history of injecting drug use to pay for health care regardless of whether they are currently employed needs to be appropriately considered within the proposed review.

iii. Addressing Barriers to Hepatitis C Treatment Services:

a. Tertiary Liver Clinics in Public Hospitals:

Peer Support Models – AIVL advocates the development and implementation of tailored peer support approaches as a fully integrated component of a multi-disciplinary team approach. AIVL believes properly resourced, supported and designed peer support models will significantly reduce a number of the barriers to treatment in the liver clinic setting identified above including:

- reducing the intimidating nature of the hospital environment;
- challenging negative stereotypes and poor attitudes among clinical and non-clinical staff;
- providing more flexible and responsive service models;
- assisting patients to develop their levels of health literacy and gain a better understanding of the 'liver clinic' environment;
- supporting patients in their clinical interactions including acting as a 'translator' or 'go-between' particularly on sensitive issues;
- supporting people through the treatment contemplation phase and reducing treatment anxiety;
- assisting people to meet their needs and requirements for hepatitis C treatment eligibility particularly on issues that people are unlikely to raise with clinical staff; and
- reduce the workload of clinical staff which can potentially provide more capacity for assessment and treatment management.

Peer Support Resourcing - Peer support for people with a history of injecting drug use in the liver clinic setting must be adequately resourced and supported with formal linkages to the relevant drug users organisation in order to provide appropriate models and adequate supervision and support for peer support workers.

Workforce Training & Support - All clinical and non-clinical staff within liver clinics should undertake training on a regular basis in relation to stigma and discrimination and attitudes and values towards people with a history of injecting drug use.

Reviewing Service Delivery Models - given the level of hepatitis C infection among people with a history of injecting drug use there needs to be research and evaluation into appropriate models of service delivery in hospital-based liver clinic settings for this patient group. This should be aimed at reduce practical and physical barriers in the clinic environment and must be conducted in consultation with peer-based drug user organisations.

Resourcing for Hepatitis C Treatment – there is an urgent need for increased funding for the number of government subsidised treatment places and to improve the clinician:patient ratio in hepatitis C treatment in hospital-based specialist liver clinics. The lack of treatment places is acting as a fundamental barrier to hepatitis C treatment access for people with a history of injecting drug use particularly as some clinicians are already reluctant to treat drug users.

b. GP Shared Care & GP Initiated Arrangements:

- **Greater Investment in GP Shared Care Arrangements** - there is a need for greater investment in GP shared care models including funding to:
 - » Support training of GPs in hepatitis C treatment and management;
 - » Engage hepatitis C focused practice nurses, nurse practitioners (NPs) and CNCs within general practice settings;
 - » Employ hepatitis C treatment peer support workers in the general practice setting; and
 - » Encourage greater interest from GPs in increasing their role in managing people in hepatitis C treatment.
- **Peer Support Models** – there is a need to conduct pilot peer support projects within a range of general practice settings with the aim of developing and documenting suitable models for effective hepatitis C treatment peer support within general practice. AIVL believes properly resourced, supported and designed peer support models will significantly reduce a number of the barriers to treatment in the general practice setting including:
 - » Increasing the willingness of general practice to participate in shared care arrangements for hepatitis C treatment;
 - » Increasing the effectiveness and cost-effectiveness of nurse-led models of care (practice nurses, NPs and CNCs) by providing them with more time to focus on assessing patients, supporting GP clinical management, liaising with the liver clinic, developing linkages, etc;
 - » Challenging negative stereotypes and poor attitudes among GPs and other practice staff by having acknowledged ‘peers’ on staff;
 - » Providing more flexible and responsive service models by using peer support workers to facilitate referrals to allied health services and community-based organisations;
 - » Supporting patients in their clinical interactions including acting as a ‘translator’ or ‘go-between’ on sensitive issues with the GP and specialist;
 - » Supporting people through the treatment contemplation phase and reducing treatment anxiety;and
 - » Reducing concerns about undergoing hepatitis C treatment with a GP who is also your pharmacotherapy prescriber by using the peer support to assist with communication issues.
- **Peer Support Resourcing** - Peer support for people with a history of injecting drug use in the general practice setting must be adequately resourced and supported with formal linkages to the relevant drug users organisation in order to provide appropriate models and adequate supervision and support for peer support workers.
- **Workforce Development** – there are a range of workforce development issues that need to be implemented to address existing barriers to GP shared care including:
 - » Development and implementation of a national training, accreditation and S100 hepatitis C treatment prescriber support program based on national competency standards;
 - » In addition to hepatitis C treatment and management skills, accreditation for S100 community prescribers should include training to address stigma and discrimination and negative attitudes towards people with a history of injecting drug use; and
 - » All nursing and non-clinical staff in practices

delivering hepatitis C treatment through GP shared care arrangements should be required to undertake initial and follow-up training on stigma and discrimination and providing non-judgmental services to people with a history of injecting drug use.

- **Increasing Access to Bulk Billing Arrangements During Hepatitis C Treatment** – poor access to bulk billing GPs has been identified as an increasing barrier to the successful delivery of hepatitis C GP shared care arrangements (McNally, 2009). There is a need for a special purpose funding arrangement under Medicare to support GPs bulk billing for consultations associated with hepatitis C treatment and management for people with a history of injecting drug use (no health care card needed). The current health system reform process could provide a unique opportunity to address this issue by developing realistic funding options to support greater participation in shared care arrangements among general practice. Such arrangements need to find the balance between the financial needs of general practice and the financial capacity of marginalised patients.

Improving Access to GPs – there is an urgent need to utilise the current health system reform process to improve access to GPs particularly in regional and rural contexts. This issue is already fundamental to the aims of the health system reform process but needs to be considered specifically in the context of managing complex and chronic conditions including hepatitis C among people with a history of injecting drug use. Improving the capacity of people on hepatitis C treatment to get a timely appointment with their GP as required during hepatitis C treatment is essential to the ongoing successful development and implementation of GP shared care arrangements. This is a major structural issue for the health system and although this recommendation is focused on access to GPs in context of hepatitis C treatment shared care, ultimately the problem will only be adequately addressed through a broader solution to the ongoing GP shortage.

c. Hepatitis C Treatment in Pharmacotherapy Settings:

- **Program Policies and Guidelines** – conduct a review of national and jurisdiction guidelines and policies governing the operation and administration of the Opioid Pharmacotherapy Program with the aim of:

- » removing unintentional barriers to hepatitis C treatment access and uptake;
- » improving program flexibility and responsiveness for those undertaking hepatitis C treatment;
- » removing punitive aspects of the program design and approach; and
- » Improving access to pain management.

- **Cost of Pharmacotherapies** – the Commonwealth and all states and territories (with the exception of the ACT) should undertake a joint process to address the growing problems and unintended consequences associated with the increasing cost of pharmacotherapy dispensing fees including:

- » Development of a nationally consistent subsidisation scheme (similar to the system in ACT) whereby the cost of pharmacotherapy dispensing is partially subsidised by government with a payment to pharmacies and clinics to partially cover their costs and a set consumer copayment of \$15 per week maximum to cover the balance; and
- » Development of a temporary program of pharmacotherapy fee support for people who are undertaking hepatitis C treatment and who:
 - Have reduced incomes as a result of hepatitis C treatment; or
 - Are living on low incomes; and/or
 - Are struggling to manage the additional health and other costs associated with hepatitis C treatment including the cost of side-effects management medications.

- **Workforce Training & Development** - all clinical and non-clinical staff within pharmacotherapy settings should undertake training on a regular basis in relation to stigma and discrimination and attitudes and values towards people with a history of injecting drug use including removing barriers to accessing pain management.

- **Confidentiality and Informed Consent** – pharmacotherapy services should undertake a review of operational practices to ensure that all policies, procedures and systems are appropriate for maintaining client confidentiality in the context of 'enhanced' service delivery such as

combined pharmacotherapy and hepatitis C treatment. Specific attention should be paid to questions such as:

- when does information about clients need to be shared with other health providers particularly in the context of multidisciplinary teams, shared care arrangements, etc;
 - how is full and informed client consent assured when information sharing does occur;
 - the unintended impacts of physically co-locating pharmacotherapy and hepatitis C treatment services; and
 - understanding the way that conflicts between pharmacotherapy and hepatitis C treatment approaches can create barriers to hepatitis C treatment.
 - **Legitimising Hepatitis C as ‘Core Business’ for Pharmacotherapy Services** – development of a national training and ongoing accreditation system for pharmacotherapy services on best practice approaches to hepatitis C prevention, diagnosis, treatment and care. This training needs to focus on building organisational cultures that support and legitimise hepatitis C service delivery as well as developing the skills and expertise of staff in clinical and non-clinical roles.
 - **Expanding Pharmacotherapy Options** – the Commonwealth and jurisdictions to work together to develop and implement additional evidence-based pharmacotherapy options as a strategy to increase drug treatment uptake and reduce barriers to hepatitis C treatment and management. These options should include heroin prescription and other injectable opioid and non-opioid pharmacotherapies.
 - **Peer Support Models** – in line with findings from piloted and evaluated peer support approaches in pharmacotherapy settings, develop and implement tailored peer support approaches as a fully integrated component of a multi-disciplinary team approach. AIVL believes properly resourced, supported and designed peer support models will significantly reduce a number of the barriers to hepatitis C treatment in the pharmacotherapy setting identified above including:
 - » positively effecting the organisational culture and general environment within the pharmacotherapy service;
 - » challenging negative stereotypes and poor attitudes among clinical and non-clinical staff;
 - » providing more flexible and responsive program approaches and service models;
 - » assisting clients to develop their health literacy in relation to hepatitis C;
 - » supporting clients in their clinical interactions including acting as a ‘translator’ or ‘go-between’ particularly on sensitive issues;
 - » supporting people through the treatment contemplation phase and reducing treatment anxiety;
 - » assisting people to meet their needs and requirements for hepatitis C treatment eligibility particularly on issues that people are unlikely to raise with clinical staff such as financial problems, housing difficulties, ongoing illicit drug use, etc;
 - » assisting people through the hepatitis C treatment process and to adhere to treatment requirements; and
 - » reduce the workload of clinical staff thereby providing more capacity for assessment and treatment management.
 - **Peer Support Resourcing** - Peer support for people with a history of injecting drug use in opioid pharmacotherapy settings must be adequately resourced and supported with formal linkages to the relevant drug users organisation in order to provide appropriate models and adequate supervision and support for peer support workers.
- iv. Addressing Others Issues in Treatment and Management of Hepatitis C:**
- a. Housing Barriers:**
- There is a need for peer-driven social research to gain a better understanding of housing issues for people with a history of injecting drug use;

- Increased resourcing needs to be made available to allow hepatitis C services to engage peer support workers to assist and support people on or contemplating hepatitis C treatment with housing issues.

b. Home Care Support:

- Funding needs to be provided for a national needs assessment and social research project on home care support needs for people on hepatitis C treatment;
- Funding needs to be provided to establish a series of peer-based home care support pilot projects with evaluation with the aim of developing best practice hepatitis C home care support models.

c. Centrelink and Income Support:

- There is a need to undertake social research to gain a better understanding of the impact of current Centrelink requirements on people during hepatitis C treatment and to recommend strategies to address any issues identified;
- There is also a need for increased resourcing to allow hepatitis C services to engage peer support workers to assist with Centrelink and other income support issues for people contemplating, undergoing and post hepatitis C treatment.

d. Post Treatment Support:

- Hepatitis C treatment services need to place a much greater priority on addressing post treatment information and support needs;
- There is a need for increased resourcing for hepatitis C peer support for people throughout the hepatitis C treatment journey;
- Further social research into post treatment support needs for people with a history of injecting drug use should be conducted.

a. Self-Management of Chronic Hepatitis C:

- There is a need to undertake peer-driven social research on hepatitis C self-management information and support needs for people with a history of injecting drug use;

- There is a need for increased resourcing for peer support to assist people to develop effective and relevant chronic hepatitis C self-management strategies;
- Hepatitis C services need increased training in alcohol and other drug issues.

ACON, Postive Life, NUAA, ASHM, Bobby Goldsmith ■

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8 Appendices

Appendix I – IDU Hepatitis C Peer Support: Key Principles and Approaches

Some key principles that underpin IDU peer-based approaches include:

- IDU peer involvement and control over the processes and outcomes;
- utilising the accumulated experience of drug using peers within the group or network;
- encouraging peers to be proactive about sharing information and knowledge with other peers and seeking out opportunities to learn from their peers;
- creating a supportive environment for drug using peers to learn and develop skills because they are with other people who they can trust, see as credible on drug issues and view as their equals;
- recognising and respecting the knowledge that each peer brings to the group through their personal experiences;
- encouraging the peer group or network to work together in a co-operative way to achieve mutual goals and benefits for the whole group;
- making use of the desire within the peer group to apply what they learn in a timely way due to the imperatives associated with illicit drug use, hep C, etc;
- building the self-esteem of peers by supporting and empowering peers to take control and responsibility for decisions in relation to their health and their lives;
- recognising the broader social, legal and cultural context that affects illicit drug users and the choices they make; and

- utilising the language, rituals and norms of the group to communicate complex and sensitive issues in a meaningful way.¹

Operating alongside these key principles is the philosophy or rationale for why peer-based approaches are effective and why they can only be done by peers which includes:

- that peers are more likely to believe and trust information, ideas and issues that come from another peer who has credibility as a user within their network or group;
- that through a shared understanding and ownership over the rituals, norms and rules of the group, information and knowledge from peers is provided in a way that is considered appropriate and takes into consideration the social and cultural context;
- that peers are more likely to listen to someone that they respect and know has personal experience of illicit drug use as opposed to government spokespeople or service providers;
- that peers have information and knowledge that has 'social currency' or is valued by others in their peer group;
- that peers often have similar priorities in their lives and understand why some issues may be more important than others at any given time;
- that peers feel comfortable with each other and that being with their peers is sometimes the only place where they can feel good about themselves, free from judgemental attitudes, discrimination and shame about their drug use;
- that peers know about changing drug patterns and issues within the peer group as they happen not weeks or months down the track so they can respond more quickly and effectively to education and support needs and changes;

¹ Madden, A, Byrne, J and Bath, N, 2002, Who's Peering at Who? Junkmail, Vol. 4, Australian Injecting & Illicit Drug Users League (AIVL), Canberra, Australia, pp.11-12.

- that peers influence each others behaviour over time and in an ongoing way that can result in more meaningful and long-term behaviour change that cannot be achieved through 'brief interventions' by outsiders;
 - that group norms are used within peer networks to reinforce 'acceptable' and 'unacceptable' behaviours which can lead to changes in behaviours that could not be achieved by those outside of the group; and
 - that peers understand the way that the group communicates through language, imagery and icons in a way that cannot be understood by outsiders.²
- It doesn't start with the assumption of "a problem." Instead people are taught to listen for how and why each person has learned to make sense of their experiences, and then use the relationship to create new ways of seeing, thinking, and doing.
 - It promotes an 'experience-informed' way of relating - instead of asking 'what's wrong', ask what happened'?
 - It examines people's lives in the context of their relationships and communities.
 - Peer support relationships are viewed as partnerships that enable both parties to learn and grow - rather than as one person needing to 'help' another.³ ■

Peer-based approaches involve ongoing and active processes of learning and skills development that are fundamentally about equals empowering each other to improve their wellbeing as a group and individually. While in reality there is as many different ways to do peer education and support as peers themselves, there are three main forms of peer education that are generally discussed these are:

1. **Organic or spontaneous education and support between peers** (such as people exchanging information while using or providing advice to a peer when being dosed);
2. **More formal or 'intentional' education and support between peers** (such as peer initiated and facilitated support groups run for intensive short periods or on a regular basis); and
3. **Formal or 'intentional' education and support undertaken by peers working in or with drug user organisations** (such as paid peer support workers who may work with individuals one-on-one, coordinate peer support groups and/or train new peer support workers).

Intentional peer support is used as an approach in many different areas including mental health, disability, HIV and as outlined above, in relation to illicit drug use and drug treatment issues and it describes a way of thinking about purposeful relationships. Sherry Mead an intentional peer support expert in the mental health area says that intentional peer support is different from traditional relationships between clients and service providers because:

² Ibid, p.13.

³ (Centre for Civil Society, Consumer, Family and Citizen Empowerment, National Update, Public Policy and Social Innovation for Empowerment, February 2009 Issue, accessed at: http://www.civilsociety.org.au/National_Update0209.htm#Sherry_Mead on 04/01/09



