BARRIERS TO HEPATITIS C TREATMENT FOR PEOPLE WITH A HISTORY OF INJECTING DRUG USE

(Edited from the more comprehensive paper: “Hepatitis C Models of Access & Service Delivery for People with a History of Injecting Drug Use”)
Introduction:

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. This is further highlighted by the fact that 75 percent of people infected with hepatitis C will develop chronic infection (NCHECR, 2009a).

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). The numbers of people accessing opioid pharmacotherapies does suggest that this setting may represent a unique opportunity for providing an integrated and supportive approach to hepatitis C treatment and management for some people with hepatitis C. Having said this however, while there is an urgent need to expand alternatives to 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 by the NSWADB also highlighted the sad fact that hepatitis C related stigma and discrimination is rife within the health system (NSW ADB, 2001). It is this type of systemic and entrenched stigma and discrimination that provides a large part of the explanation for the extremely low levels of hepatitis C treatment uptake. While the levels of treatment uptake among people with a history of injecting drug use is not well monitored, the 2006 Hepatitis C Estimates and Projections Report stated that 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. While there is evidence to support that some people like the ‘one-stop shop’ convenience of offering hepatitis C management and treatment in pharmacotherapy settings (Treloar, 2010b), not all people will want to receive treatment for or management of their hepatitis C in the pharmacotherapy setting. Furthermore, discussions about increasing the availability of hepatitis C treatment in pharmacotherapy settings has included an insufficient focus on 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 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 many people with a history of injecting drug use are not accessing hepatitis C treatment and what can be done about this situation, that AIVL developed a new national discussion paper on *Hepatitis C Models of Access and Service Delivery for People with a History of Injecting Drug Use*. That document has formed the basis for this much briefer paper developed specifically for a discussion on barriers to hepatitis C treatment for one of the main national advisory committees on BBVs & STIs. AIVL strongly encourages readers of this document to take the time to read the larger discussion paper. The main reason for this is that it addresses barriers to access and service delivery across the entire hepatitis C prevention/care continuum rather than treating barriers to ‘prevention’, ‘testing & diagnosis’ and ‘treatment’ as isolated issues. Although there is a need to address specific strategies targeted at removing existing barriers to hepatitis C treatment, ultimately if we wish to provide appropriate and effective care for those most affected, we need to address hepatitis C in the context of people’s entire lives.

Barriers to hepatitis C treatment for people with a history of injecting drug use is a complex issue that is difficult to address in just a few pages. For this reason, we have divided this paper into three sections each which will address one of the key aspects of identifying and addressing existing barriers to hepatitis C treatment. Throughout the document, unless otherwise specified it should be taken as read that the issues and actions are focused on the needs of people with a history of injecting drug use (for further discussion on the use of this terminology see the more comprehensive AIVL *Hepatitis C Models of Access and Service Delivery for People with a History of Injecting Drug Use* paper). The three sections covered in this paper are:

1. **Background on Current Barriers to Hepatitis C Treatment**;
2. **The Role of Peer Support in Addressing Barriers to Hepatitis C Treatment**;
3. **Barriers to Hepatitis C Treatment**:
   a. **Systemic Barriers to Hepatitis C Treatment**; and
   b. **Environmental Barriers to Hepatitis C Treatment Among Existing Services**.

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 can no longer afford to 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. AIVL acknowledges the important and high quality services and work that are already underway in relation to hepatitis C treatment access. We have not sought to deny this work, in fact we have tried to highlight 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 we must address.

### 1. Background on Current Barriers to Hepatitis C Treatment:

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”. Some of the key aspects of such a partnership between medical practitioners and clients outlined in the document include:

---

4 | Page  **Barriers to Hepatitis C Treatment for PWHIDU**
• 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 broadly supported in so far as they are consistent with accepted models of primary health care and chronic care management. 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. It 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’ highlight a more 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 holding these concerns. The National Hepatitis C Strategy 2010-2013 also 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 the development of 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 management and care that stike the right balance between specialist and mainstream service delivery. Any review of the current guidelines must also address the specific needs of people with a history of injecting drug use as the group most affected by hepatitis C. This process of review will not only need to 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 change within the Australian health system. In this context, a strategic and planned approach to the review and revision of current models of access and care for hepatitis C becomes paramount.

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 including 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. 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 was asked to provide paper on addressing barriers to hepatitis C treatment for the BBVS Sub-Committee.

2. The Role of Peer Support in Addressing Barriers to Hepatitis C Treatment:

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 can result in a breakdown in communication and trust between 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).

When seeking to address barriers to hepatitis C treatment 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 establish 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 (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.

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, many 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, participants, 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. 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 and remaining engaged with health care services. AIVL believes 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:**

Research has shown that genuine hepatitis C 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 with full pre and post test discussion. People were also interviewed about the reasons why they hadn’t tested and their levels of knowledge of hepatitis C and related risk factors. The project identified some very important factors in relation to barriers to service delivery and, in particular in relation to hepatitis C treatment and management. 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, management and treatment of 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 AOD and HCV specialists with information to facilitate improved health care relationships when treating patients with substance use issues 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. It is very important that people do not feel rushed into treatment decisions before they are ready or that they are wasting the time of specialist physicians with ‘frivolous’ enquiries.

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 pressient 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 clinic 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.

(See recommendations on the need for fully integrated IDU peer support in hepatitis C treatment settings in section 3b of this paper.)

3. Barriers to Hepatitis C Treatment:
Addressing barriers to treatment 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 from 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 to hepatitis C treatment.

a) Systemic Barriers to Hepatitis C Treatment:

Social, Legal, Economic & Cultural Determinants of Health:

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).

There is a “universe of social factors” that create 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)

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.

Despite 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 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. Structural violence is described 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).

When understood in this context, 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. 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:

- 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).

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 treatment and management 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).

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).

Market research 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 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).

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
As the issues above highlight, actual and assumed injecting drug use behaviour underpins the vast majority of hepatitis C related stigma and discrimination. The question remains however, what is 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? As already identified, 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:

“A 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 it is] therefore the most resistant form of discrimination.” (Watchirs, 2010)

AIVL believes that no discussion of the existing barriers to hepatitis C treatment for people with 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 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 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 illicit 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 illicit 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 detail in the larger Hepatitis C Models of Access & Service Delivery paper, 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. 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 (ADBNNSW, 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 but 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 and people in drug treatment, it is often near impossible for people prove that the poor treatment was on the grounds of hepatitis C/drug treatment 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 identified as a process of ‘symbolic violence’ (Treloar, 2010). This is 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 system (Treloar, 2010). It is also this process that leads the general public to almost unconsciously accept 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. This has been described 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. This is reinforced by services including some hepatitis C treatment services that require people to be abstinent from illicit drug use to access treatment or at least give the impression that abstinence is a requirement.

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.’

**Addressing Systemic Barriers to Hepatitis C Treatment:**

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 there is an urgent need to commence a process of legislative and policy reform to review our entire approach to illicit drugs (and the attitudes that our current approach engenders) as an integral part of removing barriers to hepatitis C treatment for people with a history of injecting drug use.
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 hepatitis C treatment 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 hepatitis C treatment 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.

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 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 ammendable 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 the current drug control laws on health of Australian citizens and ensuring public health outcomes are always the priority.

It is not possible in a document of this kind to comprehensively explore the process of reform that needs to occur. 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. Rather than viewing the reform process as something that is yet to begin however, AIVL believes it is possible to argue that this process is already underway within the community. Reforms occuring in other countries, recent statements from Australian parliamentarians, the priorities in the national strategies and the increasing 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 hepatitis C treatment for people with 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 (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 human 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 need to progressive occur:

1. **Continued expansion of diversionary schemes;**
2. **Implementation of decriminalisation approaches;** and
3. **Review and reform of legislative 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 more useful to think about how diversion, decriminalisation and regulation 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 illegality and criminalisation. 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 have a good understanding of the current legislative and policy context and explore some of the pros and cons associated with each of the strategies outlined above. While it is not possible to provide such detail in this brief paper, members can find a more in-depth exploration of the benefits of drug law reform including the growing international evidence base to support such reform in the larger Hepatitis C Models of Access & Service Delivery document from which this paper has been drawn. For the purposes of this paper we will move immediately to concrete recommendations on harmonising current drug control laws with public health approaches and outcomes.

**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. 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. 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, automatic diversion eligibility for persons charged or convicted of non-violent drug related offences, 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:**
o 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;

o 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:

  o 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;

  o 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;

  o 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 hepatitis C treatment for people with 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 hepatitis C treatment outlined above. 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 hepatitis C treatment access that work for the majority of those affected.

b) Environmental Barriers to Hepatitis C Treatment Among Existing Services:

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 treatment services that are best described as ‘environmental’ barriers. What follows therefore is a brief overview of the existing service models in hepatitis C tertiary care, identification of the main barriers to access and service delivery within these models and a range of key recommendations for addressing these existing barriers. In addition, there is also consideration of some ‘overarching’ environmental barriers that are relevant to all service models or types. This is followed by a brief assessment of a number of broader service gaps and support issues for people with chronic hepatitis C and a history of injecting drug use that are not addressed under the existing service models above. The recommendations from the above assessment also attempt to take into account opportunities that may arise from the current process of reform in the Australian health system.

**General/Overarching Barriers 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 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 something they did many years ago.

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. The need for long periods of treatment contemplation and 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).
AIWL 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 indentified 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 particularalry difficult.” (McNally, 2004)

Practical barriers to treatment 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 acknowledge 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) 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 simple 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 honest 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.

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 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.

Recommendations to Address Barriers to Hepatitis C Treatment 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. 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 reducing 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) **Barriers to Hepatitis C Treatment in GP-Shared Care Models:**

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 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.
Barriers to Hepatitis C Treatment for PWHIDU (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 potential for poor testing experiences to negatively impact on hepatitis C treatment is explored in detail in the “AIVL Hepatitis C Models of Access & Service Delivery” paper. 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. 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 or clinical trial arrangements, 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 cared 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. 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.

**Recommendations to Address 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 hepatology nurses (including practice nurses, NPs and CNCs);
  - 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 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:
  o Development and implementation of a national training, accreditation and S100 hepatitis C treatment prescriber support program based on national competency standards;
  o 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
  o 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) 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) Barriers to 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 ongoing 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.

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).

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 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, blood platelet or thyroid problems, 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 pharmcotherapy 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 is not a sufficient priority 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.

### Recommendations to Address Barriers to Hepatitis C Treatment in Pharmacotherapy Settings:

- **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.
• **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:
  o 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
  o 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:
  o when does information about clients need to be shared with other health providers particularly in the context of multidisciplinary teams, shared care arrangements, etc;
  o how is full and informed client consent assured when information sharing does occur;
  o what are the unintended impacts of physically co-locating pharmacotherapy and hepatitis C treatment services; and
  o how do conflicts between pharmacotherapy and hepatitis C treatment approaches 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. One of the 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 can make 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.

**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 owning 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-statured 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, disfunctional 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.

Recommendations to Address 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.

**Recommendations to Address 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.

**Recommendations to Address 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).

Despite the availability of some post treatment information through drug user organisations and hepatitis councils, one of the main problems is that post treatment 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.

Recommendations to Address 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 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). *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 effect 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).
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.

**Recommendations to Address Barriers to Self-Management of Chronic Hepatitis C:**

- Undertake peer-driven social research on hepatitis C self-management information and support needs for people with a history of injecting drug use;
- Increase resourcing for peer support to assist people to develop effective and relevant chronic hepatitis C self-management strategies;
- Increase training within hepatitis C services on alcohol and other drug issues.

**References:**

A complete listing of all references used in this paper is contained in the full version of this document titled: “Hepatitis C Models of Access & Service Delivery for People with a History of Injecting Drug Use” available on the AIVL website.