POLICY POSITION

Access to Hepatitis C Treatments
Discussion

Hepatitis C is the most common notifiable communicable disease in Australia, with an estimation of as many as 1.1% of all Australians infected with the virus. The continued expansion of the epidemic is alarming, with up to 16,000 incident cases estimated annually\(^1\). With the securing of the blood supply and the implementation of stringent infection control procedures in health settings, people who inject illicit drugs now comprise the overwhelming majority of new infections. There is as yet no preventive vaccine against Hepatitis C infection and no proven “cure”, but antiviral and immune-response therapies are continually improving. Current combination treatments with ribavirin and alpha-interferon and pegylated interferon monotherapy trials are successfully achieving sustained responses (where viral load becomes undetectable after 6 months) in 40 to 50% of cases. Despite comprising the majority of both new and prevalent cases of hepatitis C, however, injecting drug users are disproportionately under-represented in the treatment population.

Illicit injecting drug use attracts a high degree of stigma and continues to attract criminal penalties in most jurisdictions. Despite some debate over cost-sharing, the equitable availability of health for all remains a basic principle of social justice in Australia. Access to health services is not granted differentially on moral grounds and is allocated on the basis of need, not upon notions of guilt or blame. As well as a source of significant levels of disability and reduced quality of life for infected individuals, hepatitis C is a public health issue with significant health, social and economic costs to the whole community. In order to reduce these community and individual cost, significantly increased rates of early detection and therapeutic intervention must be promoted, along with prevention initiatives. Furthermore, the active participation of people who inject drugs is a vital factor in the hepatitis C prevention effort.

Clinical Issues

The National Health and Medical Research Council (NHMRC) Clinical Guidelines governing S100 drugs no longer exclude access on the basis of a person being an injecting drug user. A clinician’s judgement on whether a particular individual is a “good risk” for successfully responding to or complying with treatment may be coloured by ill-informed and prejudicial assumptions about illicit drug use and drug users. In many states of the USA, access to liver transplants is denied where the person is engaged within a pharmacotherapy based drug treatment program. Such blatant discrimination rarely if ever occurs in Australia, but judging all people who inject/use illicit drugs according to stereotypical ideas is unfortunately too common throughout the health system. Sadly, it is still the case that only a minority of the people eligible get as far as engaging with Hepatitis C treatment specialists. This is because they do not engage with health providers at any level due to their experience of discrimination and loss of personal dignity.

It is not enough that Hepatitis C service providers are skilled in dealing with IDUs in an affirming and non-judgemental fashion while GPs and hospital staff in general continue to justify IDU fears. Diminished access to hepatitis C treatments is but one aspect of the relative burden of ill-health experienced by IDUs; the problem is deeply imbedded within the institutions and culture of our health system and needs addressing comprehensively through improved education and workforce development, the establishment of clients charters and quality assurance standards that address users’ needs, and effective antidiscrimination campaigns.

Given the increasing success of hepatitis C treatment, it is vital that those that choose to enter into treatment are able and supported to do so. In addition, treatment must be seriously considered as a potential efficient way in which to reduce the current pool of hepatitis C infection.

\(^1\) Australian National Council on AIDS, Hepatitis C and Related Diseases Hepatitis C Sub-Committee; Hepatitis C Virus Projections Working Group: Estimates and Projections of Hepatitis C Virus Epidemic in Australia 2002
Position

People who inject illicit drugs make up the larger portion of the population affected by Hepatitis C in Australia and the overwhelming majority of those who become newly infected. However, people who currently inject are disproportionately under-represented in the population receiving antiviral and other therapeutic hepatitis C treatments.

1. It is AIVL’s position that access to health services must be based on the needs of individuals and communities and upon the equal rights of all to health. As a matter of social justice, it is the duty of governments, service providers, NGOs and the community to address the social, economic or structural factors that limit the ability of any group in society to enjoy good health or that disadvantage them with respect to access to services. According to these principles, IDUs, whether currently injecting or not, deserve equal and appropriate health services, including unencumbered access to hepatitis C treatments.

2. Key factors contributing to relatively poor access to treatments include:
   - **The economic and social marginalisation of users.** Current drug policies and ensuing stigma around injecting drug use have contributed to a legislative, social and economic environment in which users tend to be generally disadvantaged in terms of access to health and services and where many users have such a weight of more immediate needs and concerns that it is difficult for them to prioritise their needs around Hepatitis C treatment. The downstream impacts of drug policies on users’ lives include high levels of unemployment, poverty, unstable housing, stigma, alienation, loss of family and social supports, and incarceration;
   - **Users’ experience of widespread discrimination within the health sector.** In every jurisdiction in Australia, users report that their experience and expectations as consumers of health services is overwhelmingly negative. Users encounter discriminatory attitudes and demeaning and poor quality treatment to the extent that as they tend to engage with the health system as little as possible. Relative to the rest of the community users tend to engage far less with the general culture of health promotion, which involves self-health monitoring and maintenance, early intervention. Diminished access to Hepatitis C Treatments is part of the broader picture in which people who inject illicit drugs bear an inequitable burden of ill-health in our society;
   - **Aspects of the ways in which Hepatitis C treatment services are structured and delivered.** Specialist hepatitis services are concentrated in major hospitals in the larger cities. User living in outer suburban areas, let alone regional and remote locations, may find the costs and difficulties of attending specialist appointments insurmountable. There are a number of initiatives promoting the enhanced role of GPs in Hepatitis C treatment provision, but the number of GPs who offer a quality service for IDUs is limited and affordable access to GPs is generally become more difficult. Clinical obstacles to treatment include the reliance upon liver biopsy to initiate treatment with S100 antiviral therapies and the associated problems many users experience around inappropriate pain relief in hospitals;

3. AIVL is committed to engaging constructively with users, health practitioners, policy makers and the research community to help promote and develop better ways of delivering Hepatitis C specific services. Removing the broader social and structural barriers to HCV treatment access for users, however, relies upon the effectiveness of AIVL’s wider agenda: working to reorient drugs policy to an evidence-based approach that focuses on the reduction of harm;

4. In individual cases, users’ access to treatment and their prospects for success may be enhanced through the delivery of services and interventions that specifically address the plethora of issues confronting users, such as assistance with housing, maintenance pharmacotherapy or other dependence treatment options, the provision of psycho-social support, financial assistance, dedicated primary health services etc;
Position (continued)

5. Decisions around treatment should be made by the individual working in partnership with clinicians. Practitioners’ assumptions about drug users and the likely impact of the treatment regime upon any drug-related problems, or the impact of any drug-related problems on treatment compliance of efficacy must be rejected in favour of sound evidence. There is no evidence, for instance, that even regular illicit heroin use is, of itself, associated with poorer treatment outcomes. Secondly, a harm reduction approach to drug use needs to be taken, where the diversity of patterns of use and the heterogeneity of the IDU population is acknowledged and where each user is viewed as a unique individual. Treatment decisions can only be adequately informed where the IDU patient feels safe enough and respected enough to be open and honest about their lived experience and their concerns;

6. Treatment goals must at all times be set by the individual and this must include the decision whether or not to undergo treatment. For many people, the inconvenience, risks, pain and side-effects of the currently available treatment regimes may be seen as too great, the potential benefit too small. AIVL policy respects the rights of all users to make their own cost-benefit analyses and decisions around Hepatitis C Treatment: AIVL’s advocacy and educational activities will be careful to objectively inform but not try to persuade HCV affected users to undergo treatment in any way. AIVL is concerned with promoting users rights to equitable treatment access, not in recruiting users into treatments;

7. AIVL has concerns around the necessity for liver biopsy as a pre-requisite for treatment and advocates the consideration of non-invasive diagnostic procedures wherever possible. Biopsy is an invasive, distressing and, in cases, extremely painful procedure. Biopsy raises the issues of analgesia, which is often a cause of great dissention between patient and providers. Clinicians need to be better informed around issues of hyperalgesia and high opioid tolerance for long-term opiate users, and to take a humane and objective approach to pain management in which the patient’s experience of pain is taken seriously and treated aggressively. Untreated biopsy pain can lead to premature patient discharge with the attendant risks of haemorrhage and infection, as well as cessation or non commencement of treatment and the reinforcement of IDU fears of mistreatment;

8. Users in or moving through custody have rights to equitable and accessible health services. Hepatitis C treatment services, including testing and counselling, need to be configured so that persons entering, leaving and moving between custodial settings receive seamless and uninterrupted treatment services. It is the responsibility of the authority ordering the detention to ensure that these services are available and accessible by detainees, people held on remand and prisoners;
**Recommendations**

1. AIVL will actively promote the improved access to treatments by users with Hepatitis C through:
   - Working with members organisations in the states and territories to disseminate information about treatments amongst user communities and to identify barriers to treatments access.
   - Working constructively with treatments providers and policy makers at National and when appropriate state/territory levels to develop and implement hepatitis C policies and treatment services that properly meet the needs of users.
   - Working at a multiple level and systemic manner to change the underlying social and structural conditions that marginalise and negatively influence the uptake of treatments by eligible IDUs.

2. That the state/territory and Commonwealth Governments fully implement the recommendations from the *Change; Report of the enquiry into hepatitis C related discrimination, Anti Discrimination Board of New South Wales.*

3. That a national workforce training initiative be developed that addresses the issues of attitude and values for those working in the hepatitis C treatment sector.

4. To develop and promote "user friendly" services and to assess where such services could be implemented from. For example, AIVL believes that the positioning of hepatitis C clinics within drug user organisations will increase access and attendance for Injecting drug users.

5. The promotion and awareness raising of the benefits from seeking hepatitis C treatment to drug users.
AIVL Member Organisations

ACT: Canberra Alliance for Harm Minimisation (CAHAMA) - 02 6262 5299
NSW: New South Wales Users AIDS Association (NUAA) - 02 8354 7300
    NT: Network Against Prohibition (NAP) – 08 8942 0570
        Territory Users Forum (TUF) – 08 8941 2308
QLD: Drug Users Network and Support (DUNES) – 07 5520 7900
    SA: SA Voice of IV Education (SAVIVE) – 08 8362 9299
        USERS Association of South Australia - 0423653896
    VIC: Victorian Drug Users Group (VIVAIDS) – 03 9419 3633
    WA: WA Substance Users Association (WASUA) 08 9227 7866

AIVL Contact Details

Postal Address:
GPO Box 1552
Canberra City
2600
ACT

Telephone: 02 6279 1600
Fax: 02 6279 1610
Email: info@aivl.org.au
Website: www.aivl.org.au