

Inquiry into Hepatitis C in Australia

This Submission has been prepared by Frank Farmer (Executive Director) and Sally Rowell (Community Services Manager) on behalf of:



We thank you for the opportunity to present this submission and would be very happy to elaborate on any points that we have made to the committee.

A) Prevalence of hepatitis C in Australia

It is estimated that there are over 230,000 people living in Australia with hepatitis C. Hepatitis C continues to be the leading reason for liver transplants in Australia (32%), however, the demand to treat and cure hepatitis C is not being met.

In 2013, over 5000 people received a hepatitis C diagnosis and 630 people died due to their hepatitis C.

People living with hepatitis C often experience stigma and discrimination, in particular people from already marginalised communities such as Aboriginal peoples, people who inject drugs, prisoners and people from CaLD backgrounds.

Whilst sharing injecting equipment remains the most likely way of contracting hepatitis C there are many people living with the virus that no longer (and have not for many years) injected drugs.

B) Early testing & treatment options in primary care, acute care, Aboriginal Medical Services and prisons.

Testing

There is currently no access to point of care testing (Rapid Testing) in Australia for hepatitis C. HepatitisWA is calling for a pilot of rapid testing to be carried out amongst high risk clients – that is people who are currently injecting drugs and accessing Needle Syringe Programs. A pilot program aiming to increase detection of HCV infection was implemented in Wisconsin (USA) during October 2013. The pilot provided rapid HCV testing to clients from four agencies providing outreach testing for HCV and NSP services. During that period, 1,255 clients were tested using a rapid HCV test, and 246 (20%) of the results were positive. Most of the infections (72%) had not previously been reported. There is significant evidence to show that people who currently inject drugs are not inclined to access conventional health services and so may never have tested for HCV. By offering rapid testing in places that are frequented by people who inject drugs, such as NSPs, then these people may be more inclined to test, which may lead to them improving their life styles, including looking at their drug use and may also further prevent transmission of HCV to others.

Many people living with hepatitis C may have at some stage in their life shared injecting equipment, this may have occurred in their early teenage or adult years. The majority of these people have gone on to lead healthy, productive, professional and private lives. They are often not inclined to disclose this period of their life with their family, friends and colleagues, or their health professionals. Many of these people may not know that they have hepatitis C and it is not

until they become unwell that they are diagnosed. GP's are also not inclined to ask their patients about previous injecting experience if the patient does not "fit the mould" of someone who might inject.

In 2012 the U.S. Centre for Disease Control and Prevention (CDC) issued recommendations calling for people born from 1945-1965 to be tested for hepatitis C. To help implement this recommendation, CDC developed a national, theory-driven multi-media education campaign entitled '*Know More Hepatitis*'. The goal of the campaign is to reduce the morbidity and mortality associated with hepatitis C by increasing testing among baby boomers so those who are infected can get linked to life-saving care. '*Know More Hepatitis*' relies on extensive formative research to identify the best strategies and messages to reach baby boomers and health care providers in order to encourage people born from 1945-1965 to get tested. New phases of the '*Know More Hepatitis*' campaign are released on a regular basis; campaign dissemination relies primarily on donated time and space from media outlets, as well as participation by academic and community partners.

A campaign similar to the '*Know More Hepatitis*' may potentially assist in reducing the "embarrassment or uncomfortableness" felt by either GPs and/or patients with regards to testing for hepatitis C, and lead to more people being aware of their hepatitis status and ultimately an improved opportunity to avoid severe liver damage or even premature death.

Treatment

Australia has a low uptake of treatment for hepatitis C, estimated to be 1.7% of people living with chronic hepatitis C in 2010 (Hepatitis Australia, 2012). The cost of hepatitis C to the Commonwealth and State budgets is significant. The Boston Consulting Group states that "For every dollar spent on treating hepatitis C, four more are spent to combat the consequences of a failure to treat and cure it." (The Boston Consulting Group, 2012)

Current treatments in Australia are tailored according to the particular genotype that a person has, with the most common being genotype 1 followed by genotype 3. Treatments for both genotypes continue to use pegylated interferon injections and twice-a-day ribavirin tablets. Since 2014 treatment for genotype 1 now includes a once-a-day tablet of simeprevir. However, Simeprevir is not recommended for use if a person has been treated previously with pegylated interferon and ribavirin, and either boceprevir or telaprevir, as there is no data to indicate that there would be a clinical benefit. Genotype 3 treatment has remained unchanged and includes a combination of weekly pegylated interferon injections and daily ribavirin tablets.

The side-effects of pegylated interferon and ribavirin can be significant, which is one reason that treatment uptake remains low. These side effects can include:

- Mild to severe mood disturbances
- Anaemia
- Slow blood-clotting
- Fatigue
- Flu-like symptoms
- Dry skin
- Rash
- Insomnia
- Decreased appetite
- Weight loss
- Hair loss

Ribavirin can also cause birth defects and is therefore not suitable for women who are pregnant or trying to get pregnant.

Additional possible side-effects related to simeprevir include:

- Skin rashes or itchy skin
- Skin sensitivity to sunlight
- Constipation
- Nausea

In Perth the majority of people with hepatitis C who are accessing antiviral hepatitis C treatment do so through tertiary liver clinics. A recent report identified significant waiting times at the tertiary liver clinics ranging from 3 months to 18 months (Edith Cowan University, 2014). Clearly any impediment to accessing services becomes a barrier for people considering antiviral treatment.

The Fourth National Hepatitis C Strategy 2014-2017 target is to increase the number of people receiving antiviral treatment by 50 per cent each year. The Strategy calls for a shift in the focus of treatment to primary healthcare settings, which will require a “concerted effort to address barriers to treatment uptake” as well as “increasing the role and capacity of the primary healthcare sector to manage hepatitis C and provide services to most at risk populations” HepatitisWA services support people living with or at risk of hepatitis C, including people who inject drugs, by providing dedicated support services and a needle and syringe program. A recent survey, administered to 60 people with hepatitis C attending the HepatitisWA Needle and Syringe Program and the WA AIDS Council Needle and Syringe Exchange Program in Fremantle, identified that almost half (48%) did not have a regular general practitioner, a third were homeless (33%), only a few had ever been on hepatitis C treatment (5%), the majority were in the 38-49 year age group (52%) and significantly, 28% identified as Aboriginal or Torres Strait Islander. 90% had never had their liver monitored and so had no idea of their liver status. 95% had never been on treatments, however, 57% indicated they would consider going on treatments in the next 2 years with another 21% saying they would consider going on to treatments in the next 2-5 years. 13% of people were unsure of when they would consider going onto treatments. 91% of respondents would prefer attending a community based clinic for their treatments and monitoring and 100% would prefer to receive support for treatments face-to-face.

As highlighted in the Fourth National Hepatitis C Strategy many people in at risk groups have disengaged from the healthcare sector and require improved access to timely high quality support services at the time of diagnosis.

Patient-centred care provided by a nurse has been shown to significantly improve chronic disease outcomes and enhance client satisfaction (Katon et al., 2010; Victorian Government Department of Human Services, 2009). A recent evaluation of nurse-supported hepatitis C shared care programs in regional Western Australia found that waiting time to start treatment and support services available to clients in the nurse-supported model to be as good as, if not better than in the metropolitan area. Key informants in the study identified high levels of patient compliance with medication and completion of treatment. Clients were also very satisfied with services provided in the nurse-supported model of care (WA Centre of Health Promotion Research, 2014).

A nurse-led, multidisciplinary, primary care hepatitis C clinic established in 2008 in New Zealand provides clients with structured plans of care to improve continuity of care. The evaluation of the clinic determined that clients (36% of whom were current injecting drug users) were better informed about hepatitis C and its treatment, and the majority had made positive lifestyle changes. They were also more likely to consider treatment over the next 5 years. Clients reported high levels of satisfaction with care, support and information received from the clinic and less discrimination compared with other health care settings (Horwitz, Brener & Treloar, 2012).

Providing access to hepatitis C treatment in primary care has also been shown to be cost-effective (Tucker, 2013).

By providing treatment clinics within community based organisations clients will have better access to peer support, assistance with, and advocacy for their psychosocial concerns. There will be a reduced waiting time for treatment, reduced burden on the tertiary liver clinics and increased capacity within the primary health sector to treat hepatitis C.

HepatitisWA believes that all people with hepatitis C should have equitable access to treatments which will not only cure hepatitis C, but do so in a way that is not so debilitating from side effects that they cannot continue to lead a relatively normal life (such as working) whilst being treated.

C) Costs associated with treating in the short term and long term impacts of Hepatitis C in the community.

HepatitisWA was disappointed with the PBAC rejecting an application to approve Sofosbuvir (Solvadi) for people living with HCV. This clinically proven drug, along with other new generational drugs have the potential to be “game changes” and ultimately eliminate hepatitis C. Whilst it is acknowledged that these drugs will be costly in the short term - it is envisaged that in the long term they will have huge cost saving implications for the Health Budget in future. As already mentioned in this submission the Boston Consulting Group state that “For every dollar spent on treating hepatitis C, four more are spent to combat the consequences of a failure to treat and cure it.” (The Boston Consulting Group, 2012). With the introduction of new and improved treatments it would mean that patients could be managed by GPs in community based settings which would take the pressure and cost off tertiary clinics, allowing them to deal with more complex cases.

D) Methods to improve prevention of new hepatitis C infections, and methods to reduce the stigma associated with a positive diagnosis through

Prevention

The wealth of research and evidence has shown that one of the most successful and effective prevention strategies against hepatitis C transmission is needle syringe programs. This is particularly evident in the *Return on Investment Report 2 (2009)* which highlighted the health, social and financial benefits associated with preventing blood borne virus transmission.

Between 2000 and 2009, the Australian Government invested \$243 million in NSP's which resulted in the prevention of an estimated 96,667 cases of hepatitis C and 32,050 new cases of HIV. \$1.28 billion dollars were saved in direct health care costs.

If patient/client costs and productivity gains and losses are included in the analysis, then the net present value of NSPs is \$5.85 billion: that is, for every one dollar invested in NSPs, \$27 is returned in cost savings.

The report states: *If NSPs were to decrease in size and number, then relatively large increases in both HIV and hepatitis C could be expected with associated losses of health and life and reduced returns on investment. Significant public health benefits can be attained with further expansion of sterile injecting equipment distribution.*

Having this wealth of evidence which identifies the benefits of NSPs and knowing that prisons have a high prevalence and high risk of transmission of hepatitis C there is still a reluctance to introduce NSPs in the prison setting. If Australia is serious about eradicating hepatitis C then access to state of the art treatments must improve, and there must be access to NSPs in prisons. We can no longer bury our heads in the sand and deny that people are injecting drugs in prison. This issue should be seen as a public health issue not as a criminal issue and should be dealt with appropriate funding and prevention strategies.

Stigma

Many people living with hepatitis C experience stigma and discrimination. This is often related to the way in which the virus is transmitted, which is predominately through the sharing of injecting equipment. It is the use of drugs and the stereotyping associated with people who use drugs that leads to stigma and discrimination. One of the most common areas for stigma to occur is within health settings. This is often evident when people who are currently injecting drugs express their desire to go onto hepatitis C treatments. They are often denied treatments if they admit to continuing to use drugs as some health professionals do not feel it is appropriate for these people to access treatments, as they believe that re-infection will be an issue. Some health professionals make an assumption that a person who is injecting drugs is sharing injecting equipment; which is often not the case. Healthcare workers can also have pre-conceived ideas that people who inject drugs are unreliable in turning up for their appointments or are non-compliant with taking their treatments. There are a number of research articles which dispute these assumptions, one such being from the Burnet Institute in Melbourne which reports that there is evidence that a significant proportion of IDUs who are treated for hepatitis C achieve a sustained virological response (SVR). In chronic hepatitis C treatment trials, the SVR rate among IDUs appears to be comparable to rates among non-IDUs. So even with this evidence and the fact that 90% of new hepatitis C infections are attributed to injecting drug use, there is a continuing reluctance to treat people who inject drugs.

Raising the profile of hepatitis C within the community is also an area in which Australia has under achieved. There have not been any national hepatitis C campaigns directed to the general public which could help break down the stigma and discrimination associated with this virus. By increasing the broader community's awareness around hepatitis C there may be an opportunity to dispel myths and break down stigma and discrimination.

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