tasCAHRD
Tasmanian Council on AIDS, Hepatitis & Related Diseases Inc.

Anglicare TASMANIA

Tasmanian Aboriginal Centre Inc.

SUBMISSION TO

House of Representatives Standing Committee on Health

Inquiry into Hepatitis C in Australia

February 2015

Introduction

This submission responds to the terms of reference set out by the House of Representatives Standing Committee on Health Inquiry into Hepatitis C in Australia. It compiles data from a range of sources to provide an account of:

- Hepatitis C prevalence in Australia, including in priority populations
- Hepatitis C early testing and treatment options available through
    - Primary care
    - Acute care
- The costs associated with treating the short term and long term impacts of hepatitis C in the community
- Methods to improve prevention of new hepatitis C infections, and methods to reduce the stigma associated with a positive diagnosis through
    - The public health system
    - Public awareness and prevention campaigns to reduce morbidity and mortality cause by hepatitis C
    - Non-government organisations through health awareness and prevention programs.

This submission will argue that the National Hepatitis C Strategies have not been resourced sufficiently to deliver intended outcomes despite the best efforts of those working and volunteering in the sector.

It should be noted that although this submission is focussed on hepatitis C, the response to hepatitis B in Australia is even less adequate than the response to hepatitis C.

The contribution of the Link Youth Health Service, the Tasmanian Aboriginal Health Service, the Tasmanian Council on HIV and Related Diseases (TasCAHRD) and other individual contributors is gratefully acknowledged.

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The following is the submission addressing the Committee's terms of reference.

Prevalence rates of hepatitis C in Australia[1]

The Kirby Institute publishes a number of reports that document:

- the prevalence of human immunodeficiency virus (HIV), viral hepatitis and sexually transmissible infections in Australia (Annual Surveillance Report);
- progress against the goals and objectives of Australia's national blood-borne virus and sexually transmissible infections strategies (Surveillance and Monitoring Report);
- the prevalence estimates of HIV and hepatitis C antibodies and sexual and injecting behavioural risk among people who inject drugs (PWID) in Australia (NSP Survey National Data Report);
- the occurrence of blood borne viral and sexually transmissible infections among the Aboriginal and Torres Strait Islander (ATSI) population (ATSI Surveillance Report); and
- the prevalence of blood-borne viruses (HIV, hepatitis B, hepatitis C) among people in custodial settings on a national basis (National Prison Entrants Survey Report).

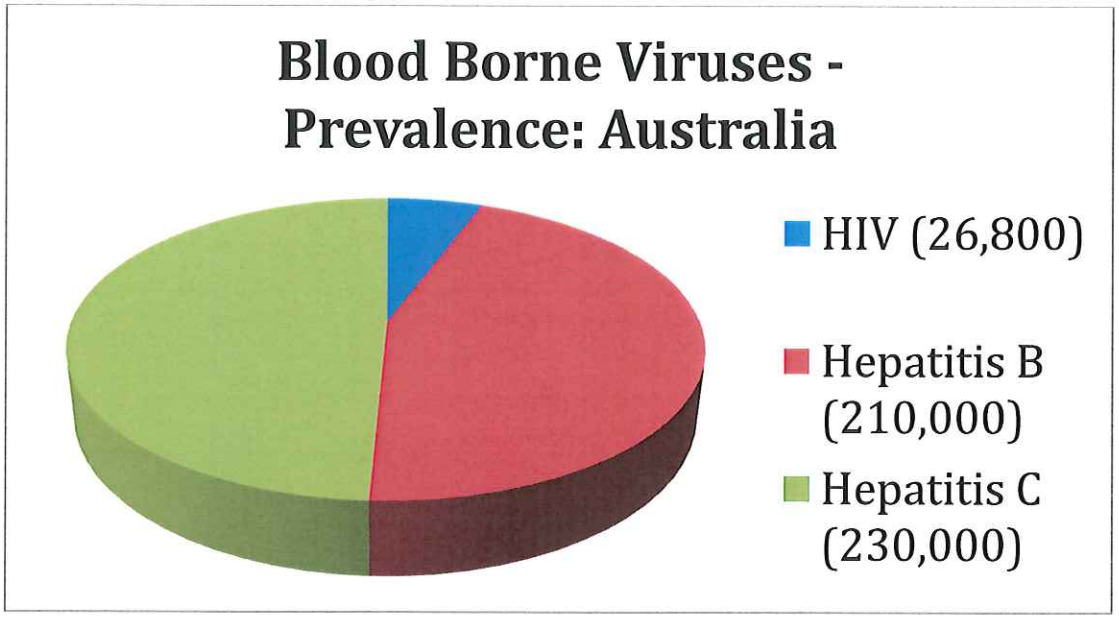
Figure 1 below shows the prevalence of viral hepatitis in relation to HIV. Australia's response to HIV has been particularly strong and represents best practice in the response to blood borne viruses. Awareness around prevention and treatment in most priority populations is high. In Australia HIV is now a manageable chronic disease.

Hepatitis C is 8.2 times more prevalent than HIV[2]. The response to viral hepatitis should match Australia's best practice response to HIV.

[1] For comprehensive prevalence data see:
- The Kirby Institute, *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2014, UNSW, Sydney, 2014*
- Inversen, J and Maher, L. *Australian Needle and Syringe Program National Data Report 2008-2012.* The Kirby Institute, University of New South Wales, 2013
- The Kirby Institute. *National Blood-borne Virus and Sexually Transmissible Infections Surveillance and Monitoring Report,* Sydney, 2013
- The Kirby Institute, *Bloodborne viral and sexually transmitted infections in Aboriginal and Torres Strait Islander people: Surveillance* and Evaluation Report, Sydney, 2014.
- Butler, T, Lim D, & Callander D. *National Prison Entrants' Bloodborne Virus and Risk Behaviour Survey Report 2004, 2007, and 2010.* Kirby Institute and National Drug Research Institute, Sydney, 2011.

[2] Based on prevalence figures from: The Kirby Institute, *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2014, UNSW, Sydney, 2014*

Figure 1: Blood borne virus prevalence 2014 - Australia[3]



In 2013, an estimated 310 000 Australians had been exposed to the hepatitis C virus approximately 230 000 of whom were living with chronic infection[4]. In 2013, an estimated 6 900 Tasmanians were HCV antibody positive (indicating exposure to the virus) with 5 100 living with chronic hepatitis C (see Table 1). Table 1 also shows that although the population prevalence of hepatitis C remains relatively constant, the burden of disease is increasing significantly over time.

[3] The Kirby Institute, *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2014, UNSW, Sydney, 2014*

Table 1: Estimated number of people living with hepatitis C by stage of liver disease: Australia and Tasmania

HCV status[5]	2003		2008		2013	
	Australia	Tasmania	Australia	Tasmania	Australia	Tasmania
Total HCV antibody positive	280 000 1.39%	6 200 1.29%	305 000 1.41%	6 700 1.33%	310 000 1.33%	6 900 1.34%
Total HCV viremic cases	210 000 1.05%	4 600 0.96%	225 000 1.04%	5 100 1.02%	230 000 0.99%	5 100 0.99%
Stage of liver disease[6]						
Living with Metavir[7] F0-F1	170 000 80.95%	3 800 82.61%	170 000 75.55%	3 800 74.51%	155 000 67.39%	3 400 66.67%
Living with Metavir F2	19 800 9.43%	440 9.57%	28 000 12.44%	630 12.35%	36 000 15.65%	790 15.49%
Living with Metavir F3	11 300 5.38%	250 5.43%	18 400 8.18%	410 8.04%	28 000 12.17%	620 12.16%
Living with Metavir F4	4 500 2.14%	100 2.17%	7 100 3.16%	160 3.14%	11 400 4.96%	250 4.90%
Decompensated cirrhosis[8]	1020 0.49%	20 0.43%	1 590 0.71%	40 0.78%	2 600 1.13%	60 1.18%

Population[9]	Australia	Tasmania
December 2003	20 008 700	480 000
December 2008	21 644 000	500 300
December 2013	23 319 400	514 000

Caution should be exercised in interpretation of the data in Table 1 as these are based on outdated estimates of the prevalence of hepatitis C in the population. For explanation of the methodology see Annual Surveillance Report methodological notes (Kirby 2014).

Although not directly comparable to the Kirby data shown in Table 1, a sample of 60 of the 310 people on the waiting list for hepatitis C treatment at the Royal Hobart Hospital (RHH) in 2014 showed that the burden of disease of hepatitis C in Tasmania may be more significant than the modelled Kirby estimates shown in Table 1.

[5] % expressed as per cent of total population

[6] % expressed as per cent of estimated total HCV viremic cases

[7] The Metavir scoring system was specially designed for patients with hepatitis C. The scoring consists of using a grading and a staging system. The *grade* gives an indication of the activity or amount of inflammation and the *stage* represents the amount of fibrosis or scarring. The grade is assigned a number based on the degree of inflammation, which is usually scored from 0-4 with 0 being no activity and 3 or 4 considered severe activity. The amount of inflammation is important because it is considered a precursor to fibrosis. The fibrosis score is also assigned a number from 0-4: 0 = no scarring, 1 = minimal scarring, 2 = scarring has occurred and extends outside the areas in the liver that contains blood vessels, 3=bridging fibrosis is spreading and connecting to other areas that contain fibrosis, 4=cirrhosis or advanced scarring of the liver.

[8] If a patient experiences any of the serious problems described below, their disease has progressed from compensated cirrhosis to **decompensated cirrhosis**. They are then at increased at risk of dying from life-threatening complications of liver disease, unless their liver can be replaced with a healthy liver (**liver transplant**): Bleeding varices (internal bleeding), Ascites (fluid in the belly), Encephalopathy (confusion), Jaundice (yellowing of eyes and skin).

[9] Australian Bureau of Statistics, Australian Demographic Statistics, Catalogue Number 3101.0, December 2003, December 2008 and December 1013

The RHH data are as follows:

Table 2: FibroScan results from a sample of people waiting for treatment at the RHH[10]

FibroScan result	Percentage of people on waiting list (n=60)[11]
F4	25
F3	14
F2	18
F1	18
F0	3
Fail	3
No show	10

There are a large number of people on the waiting list for treatment at the RHH who have not been FibroScanned[12] and may be living with advanced liver disease. This is likely to be the case in other regions of Tasmania given there is no access to FibroScanning or ultrasound elastography technology outside of the south of the State.

In all regions of Tasmania the demand for treatment outstrips supply even with severe triage practices in place. The dilemma for practitioners in such a resource-constrained environment is obvious.

Nationally, over the past 10 years it is estimated that there has been a 115% increase in people living with moderate to severe liver disease. There were an estimated 630 deaths attributable to hepatitis C in Australia in 2013. The Kirby Institute suggests that the epidemiology of hepatitis C combined with the natural history of hepatitis C infection will result in a markedly increased burden of disease over coming years. Tables 1 and 2 above show a significant increase in the burden of disease in both Australia and Tasmania between 2003 and 2009.

Kirby Report data also suggests that the number of people receiving antiviral treatment for hepatitis C has declined over the past four years in Australia. In Tasmania, treatment rates are lower than the rest of Australia. Due to significant resource constraints, people can wait for treatment for five to ten years and triage can be more rigorous than in other states. For example, the Royal Hobart Hospital targets treatment exclusively to people with advanced fibrosis or cirrhosis.

Access to treatment is a threshold issue nationally and is even more critical for Tasmania, where treatment is heavily rationed.

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[10] Methodological note: It is not clear if the RHH sample was of those waiting for their first appointment or those who have had an initial assessment and are undergoing waiting for a follow-up appointment. Patients with later stages of disease may also be more likely to be referred compared with those with earlier stages of disease. Those with earlier stage disease may be more likely to be in the 'fail' and 'no show' categories. Each of these factors could bias the sample to represent a higher proportion with later stage disease.

[11] 101% due to rounding error.

[12] FibroScan® is a non-invasive device that assesses the 'hardness' (or stiffness) of the liver via the technique of transient elastography. Liver hardness is evaluated by measuring the velocity of a vibration wave (also called a 'shear wave') generated on the skin. Calculations are used to convert the results to a Metavir score (F0 –F4).

Under-resourcing of implementation of the national hepatitis C strategies at both the national and state levels has resulted in minimal progress against the objectives of the strategies despite the best efforts of those working and volunteering in the sector. To improve outcomes for people at risk of or living with hepatitis C it is critical that the implementation of the Fourth National Hepatitis C Strategy (2014-2017) is appropriately resourced to deliver intended outcomes.

During implementation planning for the new National Strategy, the Commonwealth government has flagged that there will be no additional resources to support implementation. The Tasmanian government has also noted that there are no additional resources being allocated to the sector. This situation is untenable if the significant and costly burden of hepatitis C is to be curbed.

Table 3: National Hepatitis C Strategy, 2010-2013 – summary progress against objectives[13]

Objective	Progress
Reduce the incidence of hepatitis C	The weak evidence available suggests that hepatitis C incidence is stable to decreasing over the timeframe of the national strategy.
Increase access to new injecting equipment through needle and syringe programs	Around one in six PWID who participate in the Australian Needle and Syringe Program Survey (ANSPS) continue to report recent receptive syringe sharing, a proportion that has remained relatively stable during the life of the national strategies. National needle and syringe distribution data indicate an increase in the number of units distributed over the same time frame. However, population-based coverage of needles and syringes is not well known.
Reduce the burden of disease attributed to chronic hepatitis C	Currently, limited rigorous data are systematically collated to allow comprehensive monitoring of hepatitis C-related burden of disease. Modelled estimates suggest that hepatitis C-related burden of disease, including advanced liver disease, is high and has increased over the period of the national strategies, but this data is based on an outdated model.
Increase access to clinical care for people with chronic hepatitis C	Data suggests that the number of people receiving antiviral therapy for chronic hepatitis C has declined over the past four years. This is likely due to people deferring treatment in anticipation of the next generation of hepatitis C drugs. However, other evidence shows that the proportion of chronically infected people receiving hepatitis C treatment is low at only 10-12%[14].
Reduce hepatitis C-related stigma and discrimination in healthcare settings	No data available on hepatitis C-related stigma and discrimination.

[13] The Kirby Institute, *National Blood-borne Virus and Sexually Transmissible Infections Surveillance and Monitoring Report*, Sydney, 2013:9.

[14] This proportion is much lower in Tasmania.

Priority Population data

People who inject drugs

Table 4 shows that in Australia the hepatitis C antibody prevalence among people who inject drugs has increased significantly from 50% in 2009 to 54% in 2013 and was slightly higher amongst females compared to males.

For Tasmania, Table 4 shows that prevalence increased slightly from 53% in 2009 to 54% in 2013, with significant variability between years. It also shows a significant difference between males and females, with reduced prevalence among males (from 52% in 2009 to 46% in 2013), and significantly increased prevalence among females (from 53% in 2009 to 64% in 2013).

However, caution should be exercised in drawing inferences from the Tasmanian data due to the relatively low number of survey participants, which may distort the results.

Table 4: HCV prevalence by gender and survey year – Australia and Tasmania[15]

	Tasmania			Australia		
	% with HCV antibody			% with HCV antibody		
Survey year	**Male**	**Female**	**Total**	**Male**	**Female**	**Total**
2009	52	53	53	49	52	50
2010	44	47	45	53	53	53
2011	40	56	46	54	52	53
2012	47	46	47	52	54	53
2013	46	64	54	53	55	54

Transmission continued to occur at the highest rate among adults aged 20-29 yeas, predominantly among people with a history of injecting drug use[16]. There is a need for improved interventions targeted at young people prior to or soon after they begin injecting.

The Australian NSP Survey National Data Report found that across Australia in 2013:

- 25% reported sharing injecting equipment (spoons and tourniquets) (excluding needles) in past month;
- 50% reported re-using their own needle in last month; and
- 6% had borrowed a needle.

Although the number of needles and syringes distributed over the past decade increased slightly, there continues to be an unmet demand for sterile injecting equipment.

People in custodial settings

In 2010, nationally the overall prevalence of hepatitis C antibody for people in prisons was 22%, a decrease from 35% in 2007. Hepatitis C antibody prevalence was higher among those with a

[15] Inversen, J and Maher, L, *Australian Needle and Syringe Program National Data Report 2008-2012.* The Kirby Institute, University of New South Wales, 2013

[16] Inversen, J and Maher, L, *Australian Needle and Syringe Program National Data Report 2008-2012.* The Kirby Institute, University of New South Wales, 2013

history of injecting drug use compared with those who had not injected and higher among women who had injected than men (68% versus 46%).[17]

Table 5: Hepatitis C antibody prevalence for people in prisons by sex: Australia and Tasmania[18]

	% with HCV antibody 2010		
	Male	**Female**	**Total**
Australia	21	34	27
Tasmania	28	0	22

Table 5 shows that the hepatitis C antibody prevalence among men is higher for Tasmania than for Australia as a whole. The data for female people in custodial settings is not reliable (only one female entrant was tested).

Caution should be exercised in interpreting this data due to the following methodological issues:

- the data is based on a two week snapshot survey
- the Tasmanian numbers are very low.

The Tasmanian Correctional Health Service has advanced data collection systems that allow it to closely track prevalence rates of viral hepatitis at any point in time. Figures from the Tasmanian Correctional Health Service give a much more reliable picture of the prevalence of hepatitis C in Tasmanian prisons.

Table 6: Antibody prevalence by sex in Tasmanian Prisons[19]

Month/Year	**% of male prison population**	**% of female prison population**
July 2011	26	32
April 2012	29	30
Aug 2012	25.5	37
Jan 2015	33.5	33

Table 6 shows that antibody prevalence in Tasmania was higher in females than males between July 2011 and August 2012. In January 2015 prevalence was similar in male and females. It also shows that for men, prevalence has significantly increased over time and for females remains relatively stable except for a spike in August 2012.

Between 2011 and 2012 the prison-acquired rate of hepatitis C varied between 10 and 12% of the total prison hepatitis C load. There is a paucity of available data on prison-acquired hepatitis C in other jurisdictions which would provide a basis for meaningful comparison. However, anecdotal evidence suggests that the Tasmanian prison acquired rate is higher than in other states.

[17] Butler, T, Lim D, & Callander D, *National Prison Entrants' Bloodborne Virus and Risk Behaviour Survey Report 2004, 2007, and 2010.* Kirby Institute and National Drug Research Institute, Sydney, 2011.
[18] Butler, T, Lim D, & Callander D. *National Prison Entrants' Bloodborne Virus and Risk Behaviour Survey Report 2004, 2007, and 2010.* Kirby Institute and National Drug Research Institute, Sydney, 2011.
[19] Tasmanian Correctional Health Services, 2015.

Aboriginal and Torres Strait Islander (ATSI) people

According to the Kirby Institute, a total of 10 715 cases of newly diagnosed hepatitis C infection were reported in Australia in 2013; 796 (7%) occurred among the ATSI population, 3 596 (34%) were among the non-indigenous population and there were 6 323 (59%) cases for which indigenous status was not reported. The rate of newly diagnosed HCV infection in the ATSI population was 142 per 100 000, three times higher than the 41 per 100 000 in the non-indigenous population[20].

There was a 29% increase in the notification rate of newly diagnosed HCV infection in the Australian ATSI population whereas the rate in the non-indigenous population remained steady.

In 2013, the majority of notifications of newly acquired hepatitis C infection among the ATSI population and non-indigenous population were attributed to injecting drug use.

Table 7: Rate[21] of diagnosis of hepatitis C, 2009-2013, Tasmania by Aboriginal and Torres Strait Islander (ATSI) Status and Year[22]

	2009	2010	2011	2012	2013
ATSI	61.2	61.5	63.1	87.4	90.3
Non-indigenous	59.9	55.4	48.0	53.9	46.8

The population rate of notification of hepatitis C infection for Aboriginal residents of Tasmania increased from 61.2 in 2009 to 90.3 per 100 000 population in 2013. In Tasmania, the rate of hepatitis C notification was substantially greater in the Aboriginal population than in the non-indigenous population and has increased significantly over time.

There is a critical need for culturally appropriate ATSI specific hepatitis C interventions nationally and in Tasmania.

Hepatitis C early testing and treatment options available through:

Primary care

There are limited opportunities for early testing and, in particular, treatment in Tasmania. The quality of care in relation to viral hepatitis in the primary setting is extremely variable and dependent on the interest in and knowledge about viral hepatitis of individual primary care practitioners.

[20] The Kirby Institute, *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2014, UNSW, Sydney, 2014*

[21] Age standardised rate per 100 000 population.

[22] The Kirby Institute, *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2014, UNSW, Sydney, 2014*

Diagnosis and Liver Monitoring

Testing for hepatitis C is available through general practice clinics throughout Tasmania.

Anecdotal evidence from a wide range of sources suggests that there are many barriers to widespread use of appropriate testing, follow up and referral for treatment within the primary care setting in Tasmania. These include:

- GPs' focus on acute treatment not preventative health due to the Medicare fee for item of service model;
- GPs not routinely asking about risk factors for hepatitis C;
- GPs' lack of understanding of hepatitis C, including diagnosis on the basis of antibody tests alone, and not understanding treatment options and pathways;
- GPs under time pressure often do not deliver appropriate pre and post test counselling, leaving patients confused about their diagnosis, liver monitoring and treatment options;
- Lack of follow-up of those with positive tests (therapeutic inertia) due to preconceived ideas about the patients involved;
- Lack of access to appropriate liver monitoring technology;
- Long waiting lists in secondary (acute) care and poor rates of attendance resulting from this; and
- The belief that better treatments are 'around the corner'.

Tasmanians do not have access to FibroScan testing. The only FibroScan equipment in the state is owned by Liver Outreach Australia (LORA) (see below). LORA provides their mobile FibroScanning equipment on loan to the Royal Hobart Hospital on an ad hoc basis to run a FibroScan clinic. LORA is in its 'wind up' phase and will be phased out in June 2015. This may mean that access to LORA's FibroScan equipment will cease at this time. In addition, mobile equipment has a much higher failure rate than the latest in situ technology. There is only one private radiography clinic in southern Tasmania that can offer ultrasound elastography[23].

Appropriate liver monitoring technology is only available in the south of the state, where there is a private provider providing ultrasound elastography. There is limited access to mobile FibroScan technology. There is no in situ FibroScanning facility in Tasmania in either the private or government sector.

Treatment

The Liver Outreach Australia (LORA) pilot program has been running in Tasmania since December 2012, designed to trial a new model of care, providing assessment, treatment and monitoring services for people with hepatitis C. Nurses and GPs participating in LORA are primarily responsible for patient care. Specialist care is provided via video conference. LORA has the only FibroScan testing equipment (mobile machine) in Tasmania.

No GPs in Tasmania are currently providing treatment for hepatitis C.

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[23] **Elastography** is a medical imaging modality that maps the elastic properties of soft tissue. Metavir scores are calculated from the results.

LORA is currently drug company funded and is being phased out in June 2015. The model of care has successfully treated a number of Tasmanians who may not qualify for treatment in the public hospital setting.

Funding for the LORA project should be continued by government.

Aboriginal health services

Testing

It is a priority of the Aboriginal Health Service (AHS) in Tasmania to provide appropriate testing to those at risk.

Testing is offered opportunistically for those who present to the clinic for other health matters when screening questions reveal risk factors. Screening is also offered as part of a routine health check (available annually) and in early pregnancy. Community members (Aboriginal Health Workers or Nurses) are involved in this process although pre and post test counselling is provided by the GPs.

Treatment

Treatment is not currently offered at the Aboriginal Health Service in Tasmania. None of the current GPs have undertaken the training that would enable them to continue the hepatitis C treatment initiated by a specialist.

Even if the GPs were appropriately trained it is thought that in the absence of specialist nursing support it would not be appropriate for them to continue care in the general practice setting. With the current low levels of initiation and continuation of therapy it is unlikely that the GPs would gain enough experience in the use of these drugs to ensure ongoing safe prescription and monitoring, given they are working in relative isolation.

The AHS would like to be part of any initiative that would increase access to treatment of hepatitis C for patients. It would provide appropriate training to it's GPs, nursing staff and Aboriginal Health Workers so that they could safely support our patients however the staff believe that external co-ordination and support will also be required for this to happen.

The AHS urges the Pharmaceutical Benefits Advisory Committee to recommend that the new antiviral treatments for hepatitis C be made available on the PBS. When this has occurred the Federal government should make the necessary funds available as a matter of urgency.

When this non-interferon treatment becomes available and should safety profiles allow, the AHS would support initiatives leading to these new medications being used in General Practice.

Acute care

Testing

Where indicated, testing is carried out in the acute care setting. Testing is dependent on the doctor's level of knowledge around risk factors and willingness to explore risk factors with patients.

Treatment

In Tasmania hepatitis C treatment is only available in the public hospital setting (with the exception of the short term LORA trial). There are long waiting lists for treatment across the state and demand for treatment continues to significantly outstrip supply.

Hepatitis C treatment is offered at:

- Royal Hobart Hospital
- Launceston General Hospital
- Burnie Hospital

Treatment in Tasmania is heavily rationed. For example, the Royal Hobart Hospital (RHH) employs one nurse practitioner, working half time, to case manage patients on hepatitis C treatment. There are approximately 310 people on the waiting list for treatment in Hobart. The nurse practitioner can deal with a maximum case load of 15 people at one time. Only those with a Metavir score of F3 and F4 are considered for treatment. It is known that there is a large cohort of people with advanced liver disease who continue to wait for potentially life saving treatment.

The human face of rationing treatment

Case Study 1: Ray

Ray is man in his early 50's who has been living with hepatitis for around 20 years. He was waiting to begin treatment having been diagnosed with F3 fibrosis. Ray has stable housing, is settled on OST but is somewhat socially isolated. He may need some support on treatment.

Ray developed liver cancer while waiting for treatment. Treatment for his liver cancer is not available in Tasmania. He has to travel to Melbourne regularly for appropriate treatment. The only hope for him is a liver transplant and his prognosis is not good.

The RHH is in the process of moving people on the waiting list back into primary care for monitoring until their disease has progressed to a stage deemed to qualify for treatment. This poses significant issues for people living with hepatitis C whose primary care provider does not have sufficient knowledge to appropriately monitor liver health.

Many people on the RHH waiting list have had failed treatment experiences with pegylated interferon and ribavirin and desperately need access to new, more effective and tolerable agents.

More detailed information was not available from Launceston General Hospital or Burnie Hospital in time to meet deadlines for this submission. It is known however, that each of the three regional treatment settings are facing demand for treatment that outstrips supply and are using different triage methods to ration treatment.

Prisons

Testing

Correctional Health Services in Tasmania has offered voluntary testing to all prison entrants since 2008. Approximately 95% of prison entrants are tested for hepatitis B and C and .

All people who are hepatitis C antibody positive are offered further RNA testing if they are being considered for treatment (viral load, genotype and IL28B). Other testing such as liver function and full blood count is done in parallel.

Treatment

Treatment options are limited because there is no specialist nurse to manage patients receiving treatment. Treatment is managed by medical officers and generalist nursing staff. Treatment is prescribed by the Correctional Health Service Clinical Director who is the only S100 certified community prescriber of hepatitis C treatment in the state.

Treatment is offered to limited numbers, dictated by budgetary constraints and staffing capacity at any given time.

Patients will only be started on treatment if the duration of their sentence is equal to or greater than treatment duration. This is due to significant rationing of treatment in public hospitals and long waiting lists which restrict the capacity for prison patients to complete treatment post release in the public hospital setting.

All patients treated in the prison setting are given comprehensive pre-treatment education, ensuring an understanding of the process, pathology, side effects, etc. Prisoners must give signed written consent to receive hepatitis C treatment.

The human face of limited access to harm reduction measures in prions

Case Study 2: Joel

Joel is a young man in a Tasmanian prison. He contracted hepatitis C through sharing injecting equipment inside prison.

He is being put on hepatitis C treatment so he decides to stop injecting and starts smoking his drugs. He wants to go on OST so that he can stop altogether. He is unable to access OST.

He is put on hepatitis C treatment at around the same time the prison bans smoking. He suddenly has no matches to smoke his drugs so has to switch back to injecting. He says that there are many people who have made the switch from smoking to injecting.

He is now at high risk of reinfection.

Prevention

Key hepatitis C prevention measures are not available in Tasmanian prisons, an extremely high risk environment for hepatitis C transmission. There is no needle and syringe program, no access to bleach or disinfectants such as Fincol, and limited access to opioid substitution treatment (OST).

There is a paucity of hepatitis C prevention and harm reduction measures in Tasmanian prisons beyond poorly resourced peer and community education delivered into prisons by community sector organisations.

The prison-acquired hepatitis C rate is approximately 10-12% of the total prison hepatitis C load in Tasmania. This is unacceptably high and preventable with the right interventions.

Despite higher prevalence in the female prison population, women in custody have reduced access to treatment in the prison setting because they usually have shorter sentences and are not able to complete treatment within the term of their sentence.

A larger cohort of people in prisons could potentially be treated if there were capacity in the public sector to continue treatment post-release. Outcomes would also improve with adequate resourcing of psychosocial support.

The costs associated with treating the short term and long term impacts of hepatitis C in the community

There have been several studies of the economic and personal financial impact of hepatitis C and other liver diseases.

The Boston Consulting Group [24] clearly shows how investments in new hepatitis C treatments will cure more people of a costly disease and provide substantial returns on investment through system wide savings in the longer term. The analysis shows that:

- Hepatitis C imposes a $252 million annual cost on Commonwealth, state and territory budgets, with a projected five-year cost of $1.5 billion.
- For every dollar spent to treat chronic hepatitis C infection, four more are spent to deal with the consequences of a failure to prevent, treat and cure it.
- Hepatitis C generates costs in several ways:

The human face of stigma and discrimination and the rationing of treatment

Case Study 3: Derek

Derek is a 55 year old man who has been living with hepatitis C for 20 years. He works in the building industry and requires a certain level of fitness to do his job. Derek recently started to become unwell and at times could not get to work.

He wanted to be fair to his supervisor so he told him that he was living with hepatitis C and it was now making him sick. Soon after this Derek found that he was required on the job less and less until eventually the work dried up altogether.

Derek has had similar experiences in previous workplaces if he tells his workmates about living with hepatitis. Derek has told people in the past in an effort to protect them should he injure himself. Derek would very much like to start treatment and get another job. He risks losing his accommodation if he can't get work soon and is making every effort to do this. At the moment he faces the long wait to begin treatment and has become depressed and anxious.

[24] The Boston Consulting Group commissioned by Janssen, *The Economic Impact of Hepatitis C in Australia, August 2002.*

    - Direct health care costs associated with both treatment and longer term consequences; and
- Many who have chronic hepatitis C are disabled and unable to work, or need to work reduced hours, thus imposing costs on government in terms of providing social benefits or on the economy in lost production. The latter are difficult to quantify.
- In Australia, in each year hepatitis C is likely to result in approximately 213 cases of liver failure (costing 5.6million), 44 liver transplants (costing $5.8 million), and 48 cases of liver cancer (costing $5.6 million).
- Australia has very low rates of treatment [the situation is even worse in Tasmania].
- There are significant supply issues in relation to treatment: fewer than one in every five patients who would like to start treatment can do so.
- While new treatment agents impose an upfront cost, the improved health outcomes would generate longer term savings.

It is important to note that this analysis does not take into account the personal costs of hepatitis C.

For further information on the breakdown of costs between individual Commonwealth Departments and state level and further information please refer to the full Boston Consulting Group Report.

Deloitte Access Economics has also assessed the economic cost and health burden of a broad range of liver diseases in Australia[25].

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

The public health system

Stigma and discrimination in healthcare settings towards people with hepatitis C is associated with negative mental and physical health outcomes as has been documented in the ashm report of 2012[26].

> "HCV is an illness that attracts a large amount of stigma and discrimination because of its association with injecting drug use, also perceived as deviant and immoral. Research suggests that health care workers often hold negative views of people with HIV and HCV, mirroring those of the general public. These negative views may then be transformed into discriminatory practices and behaviours ranging from subtle or overt discrimination within the health care sector may have a major impact on receipt of care and may act as an impediment to disclosure, testing and treatment[27].

The report makes three key recommendations:

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[25] Deloitte Access Economics on behalf of The Gastroenterological Society of Australia/Australian Liver Association, *The economic cost and health burden of liver diseases in Australia,* January 2013.
[26] ashm, *Stigma and Discrimination around HIV and HCV in Healthcare Settings: Research Report,* Sydney April 2012.
[27] ibid:5.

1. The implementation of a communication/education campaign targeting health care workers to increase knowledge with a view to decreasing stigmatising beliefs and discriminatory behaviour.
2. Further research into protective and resilience building factors for people living with HCV.
3. Policy support for these recommendations through [local state-based] strategies.

This issue around stigma and discrimination also applies in the primary care setting and strategies are urgently needed to address this significant barrier to people accessing appropriate health care.

Public awareness and prevention campaigns to reduce morbidity and mortality caused by hepatitis C

Increasing public awareness aimed at reducing morbidity and mortality depends on the ability of the primary care sector to diagnose, monitor and refer for treatment.

It also depends on the ability of the system to ensure that supply meets demand for treatment.

The quality of primary care and access to treatment are threshold issues.

Non-government organisations through health awareness and prevention programmes.

Anglicare Tasmania – Hepatitis Prevention Program

Anglicare Tasmania delivers Tasmania's only dedicated Hepatitis Prevention Program (HPP) within a severely resource-constrained context. The Program is for people living with viral hepatitis (hepatitis B and C in particular) or at risk of acquiring it, and the services that work with them.

The Program is targeted to the following priority populations:

- people who inject drugs
- people in custodial settings
- Aboriginal community
- culturally and linguistically diverse communities
- young people
- women
- people in geographically isolated communities.

The program employs one person with lived experience who manages the Program and one non-peer support worker, a total of 1.5 FTE. The Program delivers a number of services.

Sector training

The Hepatitis Prevention Program offers training for service providers and community groups tailored to their needs.

Community Education

The Program delivers education sessions directly to priority populations and attends relevant community events to talk to people about viral hepatitis.

Peer Education

The Program has delivered peer education programs primarily targeted to PWID. It is about to commence an incentivised peer education pilot project based on the Deadly Liver Mob that operates out of the Mount Druitt NSP in Western Sydney to assess whether the model will work in the Tasmanian context. The model is collaborative and links participants to clinical services.

Hard to reach populations require innovative health promotion approaches. Peer education:

- is more acceptable than mainstream support services to marginalised groups;
- provides and effective means to reach target groups so they can access help;
- assists in building self sustaining networks for isolated groups;
- helps to challenge stigma and discrimination by reframing negative perceptions;
- provides ongoing personal development opportunities;
- is cost-effective;
- is credible to members of marginalised target communities;
- empowers participants to change their behaviour and influence others;
- provides an efficient means of transferring knowledge;
- is strengths-based and non-judgmental; and
- provides learning opportunities through role-modelling.

Incentives are being used to improve the level of engagement with a stigmatised and marginalised community that experiences significant barriers to engaging with services, particularly clinical services.

This is a pilot program only. If successful it should be resourced to continue and expand roll out across the state and potentially into other priority populations.

Information

The Program delivers one to one brief interventions to people covering a range of issues including:

- prevention and transmission, including harm reduction and safer drug use;
- living with hepatitis;
- working with a GP to ensure appropriate liver monitoring;
- access to treatment;
- what to expect from treatment; and
- referrals to other services.

It also provides a range of written resources on viral hepatitis.

Support Service

The HPP provides practical and psychosocial support to people living with hepatitis to increase their readiness for treatment. It also provides support to people undergoing treatment by helping with transport to treatment, information, advocacy and referral to other appropriate services with the aim of encouraging adherence to treatment and completion of treatment.

The Support Service assists treatment providers by picking up some of the psychosocial support or case management they would otherwise deliver to their patients thereby allowing them to increase their focus on the clinical aspects of a patient's treatment.

The Support Service is only available in the south of Tasmania. Anecdotal evidence suggests that the provision of a similar service for Burnie and Launceston treatment sites would improve access to treatment and outcomes for patients.

Anglicare Tasmania NSPs

Kwon et al[28] has evaluated the impact and cost-effectiveness of NSPs with respect to HIV and hepatitis C infections among people who inject drugs in Australia.

Their modelling demonstrates that NSPs have been effective in preventing both HIV and HCV transmission among PWID, are cost-effective in the short term and are cost saving when future health outcomes and costs are considered.

> "It is important to note that this study assesses only the impact of NSPs in averting HIV and HCV infections among IDUs. It does not include other benefits such as preventing injecting-related injuries, psychosocial support and referral, education and prevention.
>
> Several other studies have demonstrated similar results in other contexts. In a systematic review of the international literature published in 2006, 13 economic evaluation studies of NSPs were identified. The studies all concluded that NSPs were cost saving or cost-effective compared to the lifetime cost of HIV.[29]

Over time, funding for Tasmanian NSPs has declined in real terms, failing to keep pace with increasing costs of staffing NSP outlets.

Anglicare operates two primary NSP outlets, one in Glenorchy (a northern suburb of Hobart) and one in Hobart city. The Hobart outlet is open daily from 12:30 to 5:00pm. It was previously open from 10:00am to 5:00pm daily. The Glenorchy outlet is open daily from 10:00am to 5:00pm, with the exception of Wednesdays (open 12:30 to 5:00pm). There continues to be an unmet demand for NSP services during the morning in Hobart.

The other primary NSPs in Tasmania are at:

- Clarence Integrated Care Centre (Rosny, an eastern suburb of Hobart);
- Bridgewater Community House (outer north eastern suburb of Hobart);
- Salvation Army Launceston; and

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[28] Kwon, J.A. et al, 'Estimating the cost-effectiveness of needle-syringe programs in Australia', *AIDS*, Vol. 26, No. 17, 2012.
[29] ibid.

- Youth and Family Community Connections (north west coast - Devonport).

There are also approximately 20 secondary NSPs across the state.

Vending machines are located at:

- Anglicare Hobart NSP, Watchorn Street, operational 24 hours a day. This machine stocks fitpacks with various items, catering to people who inject street drugs, and those who inject pharmaceutical drugs.
- The local Post Office in Invermay, Launceston supports a vending machine with a limited range of equipment available.
- The Council Chambers at Devonport supports a vending machine with a limited range of equipment available.

It is understood that the Tasmanian Department of Health and Human Services is exploring opportunities for the further roll-out of vending machines in the state. Although a welcome initiative, vending machines cannot duplicate the broad range of services delivered through NSPs.

A number of chemists supply a limited range of equipment (usually fitpacks containing 1ml syringes). There are a significant number of Tasmanian pharmacies that participate in both the NSP and OST. This can be a barrier to some people who are understandably reluctant to collect injecting equipment from the same service that administers their OST. This further hinders access to sterile injecting equipment for people who inject drugs in regional and remote areas.

A number of other services do work in the hepatitis sphere in the absence of dedicated funding including:

TasCAHRD

TasCAHRD's organisational vision is a society that values, respects and embraces diversity. Our mission is to work in partnership with targeted communities to promote health and well being that enhances the capacity of individuals to achieve quality of life and reach their full potential.

TasCAHRD's target communities include;

- people living with HIV and/or viral hepatitis; (PLHIV / PLVH)
- gay men and other men who have sex with men; (Gay Men and MSM)
- people who inject drugs (PWID)
- culturally and linguistically diverse (CALD) communities adversely affected by, or at increased risk of, HIV and viral hepatitis;
- other people at risk of HIV and/or viral hepatitis; and
- lesbian, gay, bisexual, transgender and intersex (LGBTI) communities.

TasCAHRD works in partnership with Hepatitis Australia, Australia's national hepatitis peak body, to provide information on hepatitis.

TasCAHRD aims to raise awareness of viral hepatitis as a cause of liver disease and the type of behaviours and activities that put people at risk of contracting the virus.

With regard to Hepatitis B TasCAHRD staff educate those who are at risk from becoming infected that there is a vaccine available that can prevent people from becoming infected. An important part of this, TasCAHRD's work is to provide easily accessible information for anyone exposed to, or affected by hepatitis B.

Information is also provided for health and other professionals who may come into contact with people living with the virus or people who are at risk from hepatitis B. The aim is to ensure that as many people as possible who may be potentially at risk of contracting hepatitis are offered the vaccine; offered testing and if diagnosed can be provided with information, treatment and support to live a healthy life.

TasCAHRD focuses on Hepatitis C, a far more insidious disease that has taken far too many lives in Tasmania. The Council is acutely aware that if left unchecked in its spread, hepatitis C will continue to impact the lives of Tasmanians and cost millions of dollars to Tasmanian taxpayers annually. It is with this in mind that TasCAHRD is continually advocating for investment in effective targeted community programs and services, more integrated models of health care delivery, and education and prevention programs that reach the most vulnerable in our community.

A national campaign was launched in November 2014, calling on Health Minister Peter Dutton to ensure new drugs are made available without delay to all Australians living with hepatitis C. TasCAHRD, alongside other Hepatitis Australia members have worked with local stakeholders in formal and informal lobbying at both a state and national level.

TasCAHRD has been instrumental in distributing the Hepatitis Report Card as a means educating service providers and the broader community about this reality.

Important aspects of TasCAHRD's work in the Hepatitis space include -

- sourcing and implement Hepatitis Australia membership benefits;
- attendance at hepatitis prevention skills development opportunities provided to Hepatitis Australia members, and disseminating this information in Tasmania;
- implementing community awareness campaigns in Tasmania, including any annual Hepatitis Awareness Week activities provided to members;
- maintaining the 1300 HEP ABC Information Line – continue to promote the line, access and respond to calls and make referrals to Anglicare where appropriate;
- referral of NSP consumers to NSP providers when they approach TasCAHRD for equipment;
- distribution of Hepatitis Australia education resources; and
- maintenance of communication channels between key hepatitis stakeholders in Tasmania e.g. Corrections Primary Health (DHHS), Anglicare and Hepatitis Australia.

TasCAHRD advocates for greater access to NSP services. Research from around the world clearly shows that NSPs make a significant contribution to preventing the spread of HIV/AIDS and hepatitis b and C. The Tasmanian drug using community needs improved options for access to sterile injecting equipment. This will only occur with greater investment.

Tasmanian Aboriginal Centre and Aboriginal Medical Service

See section above. There is a need for a dedicated Aboriginal hepatitis prevention worker to deliver culturally appropriate hepatitis prevention programs and harm reduction. If funding was secured for such a worker they could be located either within Anglicare's hepatitis prevention program or in the AHS (with mentoring from the HPP) or employed within a partnership between the two services.

The Tasmanian Aboriginal Centre operates NSPs in Hobart and Launceston.

For further

The Link

The Link Youth Health Service (The Link) provides a wide range of services to young people aged 12 to 25 (inclusive).

The Link runs an NSP outlet onsite Monday to Friday generally 9am to 5pm. Because the NSP has a low volume of clients, there is very good opportunity for brief interventions and education through the outlet. Many of the people who use the NSP at The Link also use other services onsite including showers, clothes washing facilities, food and information on nutrition, free condoms, a mail holding service and secure lockers to keep personal belongings. Young people also have access to Youth Health Workers without needing an appointment.

The Link manages Headspace Hobart and employs some clinical staff. There are GPs, counsellors and psychologists as well as Sexual Health clinical staff. There is no hepatitis C testing being done at The Link, but there is potential for this and for support to be offered to young people diagnosed with hepatitis C, given adequate resourcing.

The Link does not currently have a specific hepatitis C program, but did in past. In 2009, The Link developed a community education and health promotion DVD (http://vimeo.com/7608495), that was produced by two local young women and awarded first prize in the World Hepatitis Alliance Awards. The Link also employed a part-time Hep C educator.

There is limited scope to provide a dedicated hepatitis C program at The Link Youth Health Service with the current available resources although there is potential for the development of collaborative programs with modest additional resources.

Gaps in Hepatitis Prevention Service Delivery

Support Services

There is a need for a support service in the North and North West of Tasmania to deliver psycho-social support to people to increase their readiness for treatment and support them to adhere to treatment regimes and complete treatment.

Education and Prevention in the Aboriginal community

Given the disproportionately high notification rates for Aboriginal people, there is a need for a dedicated Aboriginal health worker to deliver culturally appropriate hepatitis prevention to the Aboriginal community.

Peer education

Peer education is a proven means to disseminate health promotion messages in hard to reach communities. Peer education strategies could be strengthened in Tasmania, particularly outside of Hobart.

Written resources

Tasmania has a paucity of local written resources. The Hepatitis Prevention Program relies on the generosity of Hepatitis Australia (through TasCAHRD) and Hepatitis Councils in other states for the supply of written resources.

There is a need for the development of local written resources for Tasmanian people.

Needle-Syringe Program

The NSP could be expanded to improve reach into regional and rural areas of Tasmania. Mobile services would be a cost-effective way to expand the reach of services.

Recommendations

Increase resourcing of the National Hepatitis C Strategy (2014-2917) implementation at both national and state levels.

Past national strategies have not been adequately resourced by either Commonwealth or State governments to deliver on intended outcomes. The Tasmanian government performs poorly in investment in hepatitis C prevention and treatment in particular.

Increase access to treatment, management and care to support people to receive treatment for hepatitis C.

Access to treatment is a key issue nationally but the situation is more critical for Tasmania. The bottleneck in the Tasmanian treatment system is lack of appropriate funding for nurse practitioner hours to monitor and manage patients' treatment.

We therefore recommend that:

- specialist nursing hours be increased at each of the three treatment centres in Tasmania;
- treatment to be provided in opioid substitution treatment settings;
- funding should be provided for the continuation of LORA and options for treatment in the primary health care setting be further explored; and
- psychosocial support for people wanting to access treatment in Burnie and Launceston be resourced.

Provide ready access to new interferon-free hepatitis C treatments.

New generation treatments are both more tolerable and effective than current treatment regimes.

- The Pharmaceutical Benefits Advisory Committee (PBAC) should immediately approve Sofosbuvir, Asunaprevir and Daclattsavir and appropriate drug combinations for subsidy to make them affordable to people living with hepatitis C.

Strengthen the role of prevention in Australia and Tasmania's response to hepatitis C.

The demand for NSP services continues to outstrip supply. Coverage of NSPs in rural and regional areas in particular requires improvement.

- Tasmania could trial mobile services to improve reach into regional areas, particularly the Huon Valley, Derwent Valley, the midlands and West Coast.
- NSPs should operate out of all hospital and community centres in Tasmania.

There is an urgent need for implementation of prevention strategies in prisons nationally and in Tasmania.

- At a minimum prisoners should be provided with access to bleach or Fincol. The preferred option is the provision of NSPs in prison.
- Improve access to OST in prison settings.

There can be waiting lists for accessing OST in Tasmania and the Tasmanian Opioid Pharmacotherapy Policy limits clinical flexibility in the delivery of OST.

- Increase access to OST in Tasmania delivered within a genuine harm reduction framework.

In Tasmania community education and sector training is under-resourced. There is a need to for adequate funding for innovative community education and sector training to improve knowledge around hepatitis C and to reduce stigma and discrimination.

- Increase resourcing of dedicated hepatitis prevention programs
- Resource the employment an Aboriginal health worker dedicated to provide culturally appropriate hepatitis prevention programs specifically serving the Aboriginal community.

Given that the risk of contracting hepatitis C in the first year of injecting is high, there is a case for delivering harm minimisation education across the youth sector and in schools. This is not limited to hepatitis education but could be extended to harm minimisation across the gamut of drug use.

- Resource the provision of hepatitis education across the youth sector and in schools.

Peer education is a proven cost-effective way to get information into hard-to-reach communities. There is a need, particularly in Tasmania, to improve resourcing of innovative peer education strategies.

- Appropriately resource innovative peer education programs.

Provide accessible testing and liver monitoring for priority populations.

There are significant barriers for priority populations to access mainstream primary care services.

- Resource the delivery of clinical services such as testing and liver monitoring alongside primary NSPs and in the OST, including pilot studies and trials of new models of service delivery.

Tasmanian people living with hepatitis do not have access to FibroScan technology.

- The RHH and Launceston General Hospital should invest in FibroScan technology to provide appropriate liver monitoring to people living with hepatitis C.

Improve the quality of primary care for people at risk of and living with hepatitis C.

GPs' knowledge about hepatitis C testing, monitoring and treatment is very uneven.

- GPs should be offered training to improve their capacity to provide appropriate care for people living with hepatitis C.
- Target health care workers to increase knowledge around hepatitis C with a view to decreasing stigmatising beliefs and discriminatory behaviour.