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Committee Secretary
Standing Committee on Health
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To whom it may concern

Submission to the Standing Committee on Health Inquiry into Hepatitis C in Australia

Attached please find our submission to the Standing Committee on Health. The three nursing organisations whose logos are included in this letter contributed to this submission and endorse its content. I am signing this letter on behalf of these nursing organisations. These nursing organisations would also be pleased to attend the hearing you have scheduled for this inquiry. Please direct any future correspondence with the contributing nursing organisations through me:

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We look forward to the outcomes of this inquiry.

Yours sincerely



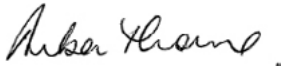
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Submission to the Senate Select Committee on Health *Inquiry into Hepatitis C in Australia*

Prepared by Australian College of Nursing (ACN), Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM) and Drug and Alcohol Nurses of Australasia (DANA).

The following signatures represent the formal endorsements from each organisation.



**Debra Thoms, CEO,
Australian College of Nursing**



**Janine Mohamed, CEO,
Congress of Aboriginal and Torres
Strait Islander Nurses and
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**Julian Grant, CEO,
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Our organisations

Australian College of Nursing (ACN)

ACN is the national professional organisation for nurse leaders. ACN is an advocate for the nursing profession, advancing the skills and expertise of nurses to provide leadership in their contribution to the policy, practice and delivery of health care. ACN is a membership organisation with members in all states and territories, health care settings and nursing specialties. ACN's membership includes many nurses in roles of influence, including senior nurses, organisational leaders, academics and researchers. ACN is also the Australian member of the International Council of Nurses headquartered in Geneva.

The Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)

The CATSINaM is the national peak body that represents, advocates for and supports Aboriginal and Torres Strait Islander nurses and midwives. CATSINaM is a not-for-profit membership-based organisation governed by a nationally elected Aboriginal and Torres Strait Islander Board.

CATSINaM's purpose is to:

honour an holistic and culturally safe approach to achieving optimal health and wellbeing for Aboriginal and Torres Strait Islander peoples and communities. We develop and promote strategies to ensure that this holistic and culturally safe approach is understood and applied by nurses and midwives working in Australia.

A key component of our work is to promote health services to become culturally safe working environments for Aboriginal and Torres Strait Islander nurses and midwives; and the promotion of Indigenous health through the improvement of health service delivery for Aboriginal and Torres Strait Islander peoples.

Drug and Alcohol Nurses of Australasia (DANA)

Drug and Alcohol Nurses of Australasia is the peak nursing organisation in Australasia providing leadership to nurses and midwives with a professional interest in Alcohol, Tobacco and Other Drug (ATOD) issues. DANA aims for excellence and the ongoing improvement of quality care in nursing in all practice contexts.

DANA actively promotes a legitimate role for nurses, midwives and their professional non-nursing peers to respond to Alcohol, Tobacco and Other Drug-related issues. In doing so, DANA promotes practice based on the best available evidence, and promotes active involvement in research in Alcohol, Tobacco and Other Drug-related interventions, and other issues relevant to the ATOD field.

DANA provides consultancy, advice and advocacy to our members, nursing organisations and key stakeholders in relation to ATOD matters, including promoting the inclusion of ATOD issues in core undergraduate curriculum, staff development programs and continuing education, and within postgraduate clinical and research degrees.

The following submission to the *Inquiry into Hepatitis C in Australia* draws on the experiences of our three nursing organisations to present key issues of concern and recommendations in relation to the prevalence, prevention and treatment of hepatitis C in Australia.

1. Recommendations

- i. Proven models of community-based hepatitis C treatment services should be expanded to improve access to hepatitis C treatment and care.
 - ii. Strategic workforce planning and development is required to ensure clinicians have the skills and knowledge to meet the needs of people with hepatitis C.
 - iii. Universal screening for substance misuse should be available across primary health care to identify people at risk of contracting hepatitis C and to support opportunities for intervention.
 - iv. Nurse-coordinated or supported models of care should be expanded to provide timely access to treatment for patients with hepatitis C.
 - v. The goals of the *Fourth National Hepatitis C Strategy 2014–2017* to improve the diagnosis and treatment of hepatitis C in Aboriginal and Torres Strait Islander people should continue to be supported.
 - vi. Screening for hepatitis C should be routinely offered on entry and discharge from the custodial system with discharge screening linked to community-based management and treatment programs.
 - vii. When eligible, a person should receive and complete hepatitis C treatment while incarcerated whenever possible.
 - viii. Trials of needle and syringe exchange programmes in prisons should be supported nationally.
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2. General Comments

The nurse workforce fulfils a wide range of clinical roles including acute medical and surgical nursing, illness prevention, health promotion and chronic care. Across the health care sector nurses practice in diverse health care settings such as in speciality tertiary medical units, correctional facilities, community drug and alcohol programs, mental health services, immigration detention centres, remote area clinics and many others. Due to their presence at the frontline of care, it is not uncommon for nurses to be directly involved in the identification, review and/or management of people who are ‘at risk’ of or who have the hepatitis C virus. Of all health professions, the nursing profession has the most extensive reach across and within communities. Their direct and frequent contact with patients, families, schools and community groups enables their extensive dissemination of health information and services across population groups. As nurses are so widely distributed throughout Australian communities they are an easily mobilised workforce to undertake a broad range of health initiatives including those aimed at improving the prevention of hepatitis C infections.

3. Comments against the Terms of Reference

A. Prevalence rates of Hepatitis C in Australia

Presence of disease in Australia

Hepatitis C represents a significant burden of disease in Australia. According to the latest publically available data, it is estimated that in 2013 approximately 310,000 people nation-wide had been exposed to the hepatitis C virus and of these, approximately 230,000 are living with a chronic infection of the virus (The Kirby Institute, 2014). Approximately 10,000 Australians contract a hepatitis C infection each year and modelling by Deloitte Access Economics predicts that the prevalence of hepatitis C will rise to more than 410,000 by 2030 (Marriott, 2014).

At risk population groups

Certain population groups are at greater risk of contracting hepatitis C, these include injecting drug users, people in custodial detention and Aboriginal and Torres Strait Islander people. The higher prevalence rates seen in these groups point to the social determinants of hepatitis C transmission.

In Australia, over 90% of hepatitis C infections are acquired as the result of sharing injecting equipment (Resnick, 2010) and 14% of people accessing syringe exchange programs have hepatitis C (The Kirby Institute, 2014).

Custodial settings

In custodial settings, the general prevalence of hepatitis C infection has been estimated to be between 23% and 47% (AIHW, 2013). Among women in prison, the prevalence is over 70% (AIHW, 2013). The high prevalence rate of hepatitis C in custodial populations is likely to be related to the fact that a large proportion of prisoners are injecting drug users or have a history of injecting drug use. In addition, prisoners have limited access to sterile injecting equipment, which significantly increases their risk of contracting hepatitis C (AIHW, 2013). The Australian Government Department of Health (DOH) acknowledges that due to a lack of national surveillance it is difficult to determine the incidence of hepatitis C infection in custodial settings (DOH, 2008). However, DOH reports that transmission of hepatitis C “undoubtedly occurs” in custodial settings with one study estimating that inmates “...have 156 times the risk of acquiring hepatitis C in prison, compared to those who might be considered ‘at risk’ in the community (Millar 2002)” (DOH, 2008). Furthermore, a 2008 study of adolescents convicted of a criminal offence found that those with a current custodial sentence had double the risk of contracting hepatitis C compared to those serving a community-based supervision order (Van der Poorten, 2008). These estimations clearly signal the need to mitigate the risks of hepatitis C transmission amongst prison inmates. Reducing or preventing the occurrence of new infections in prison will not only reduce the prevalence of hepatitis C amongst inmate populations (including staff exposure) but also its prevalence within the broader community if prison discharges leave prison without acquiring a new hepatitis C infection.

Aboriginal and Torres Strait Islander populations

The Aboriginal and Torres Strait Islander population has a disproportionately high rate of hepatitis C infection. While Aboriginal and Torres Strait Islander people make up less than 3% of the Australian population, they represented more than 8% of those living with hepatitis C in 2009 (Resnick, 2010). Depending on location, the incidence of new infections in Aboriginal and Torres Strait Islander populations has been estimated to be between 2% and 10% higher than

non-Indigenous populations. The overrepresentation of Aboriginal and Torres Strait Islander people among injecting drug users and custodial populations is likely to be a contributing factor to the high prevalence rates of hepatitis C in this demographic (Resnick, 2010).

Drawing attention to the high and rising prevalence of hepatitis C is important because of the profound negative effects it can have on an individual's health, life expectancy and ability to participate in social and economic life. Around 80,000 Australians have moderate to severe liver disease related to hepatitis C infection (The Kirby Institute, 2014). It is estimated that between 400 and 880 deaths attributable to chronic hepatitis C occurred in 2013, and hepatitis C was the underlying cause of liver disease in 30% of liver transplants performed in that year (The Kirby Institute, 2014). People infected with hepatitis C also experience stigmatisation and discrimination, including from health care professionals, which can impact on their ability to access health services and social support (Cama, 2015). In addition to its impact on individuals, the increasing prevalence of hepatitis C is also likely to have a significant impact on already over-stretched health services, requiring workforce development and new models of care.

B. Hepatitis C early testing and treatment options available through primary care, acute care, Aboriginal Medical Services and Prisons

Recommendations:

- *Proven models of community-based hepatitis C treatment services should be expanded to improve access to hepatitis C treatment and care.*
- *Strategic workforce planning and development is required to ensure clinicians have the skills and knowledge to meet the needs of people with hepatitis C.*

Australia's rates of testing and diagnosis are high in comparison to other developed nations (BCG, 2012) (DOH, 2014), as a result of successful opportunistic screening programs in prisons, drug and alcohol treatment centres, antenatal clinics and sexual health services (BCG, 2012) (DOH, 2014). However, 40,000 to 50,000 people with hepatitis C remain undiagnosed and unaware of the potential impact of hepatitis C on their health and the health of others (BCG, 2012) (DOH, 2014). Australia's *Fourth National Hepatitis C Strategy 2014–2017* acknowledges that there is a need to improve hepatitis C testing rates, particularly in high risk populations (DOH, 2014).

Despite Australia's high rate of diagnosis, it is estimated that less than 2% of patients with hepatitis C access treatment each year (Gidding et al., 2009). Treatment is not recommended for some people, including patients with decompensated cirrhosis or severe psychiatric illnesses, due to the potential for complications. Among those who are candidates for treatment, there are a variety of reasons for the low uptake of hepatitis C therapies, including barriers to accessing treatment services, the length of treatment and the significant side effects associated with current antiviral treatments. However, studies have demonstrated that a large proportion of patients can be treated successfully if appropriate infrastructure and supports are in place (Hellard et al., 2012).

New treatment options with less significant side effects are likely to become available in the future. The availability of interferon-free treatment options is likely to increase demand for treatment, potentially placing pressure on existing treatment services. It is critical that planning is undertaken to ensure that health services will be able to meet the increased demand for hepatitis C treatment.

While new treatment options are on the horizon, there are many people living with hepatitis C who cannot wait for next generation treatments to become available. Governments and health services must commit to maximising access to current treatment options, including among the most disadvantaged populations. Increasing access to treatment will require expanding successful models of community-based hepatitis C treatment services and supporting workforce development to ensure clinicians have the skills and knowledge to meet the needs of people with hepatitis C.

Our organisations suggest implementing the following strategies to increase access to testing and treatment through primary care, acute care, Aboriginal Medical Services and correctional facilities.

Testing and treatment options in primary health care

Recommendation: *Universal screening for substance misuse should be available across primary health care to identify people at risk of contracting hepatitis C and to support opportunities for intervention.*

The misuse of legal and illegal substances can have a significant negative effect on a person, their family and the community. Universal screening for substance misuse in primary health care settings provides an opportunity to identify the risks and harms associated with substance misuse and to provide a brief intervention.

The Alcohol, Smoking and Substance Involvement Screening Test (ASSIST), developed by the World Health Organization, was designed for use by health professionals in primary health care settings. The ASSIST asks people about their experience of using alcohol, tobacco and other drugs across their lifetime and in the past three months. The ASSIST specifically asks about injecting drug use, providing an opportunity for an intervention to discuss the risks of injecting and harm minimization options (Henry-Edwards et al., 2003). Thus, the ASSIST provides an opportunity for the issue of Hepatitis C testing to be discussed. The introduction of the ASSIST into the range of primary health care settings throughout Australia would raise awareness, initiate conversations around injecting drug use; educate injecting drug users; help reduce transmission of hepatitis C via needle and equipment sharing; and identify at risk people for testing and referrals into treatment.

Nurse-coordinated/supported shared care programs

Recommendation: *Nurse-coordinated or supported models of care should be expanded to provide timely access to treatment for patients with hepatitis C.*

The successful delivery of testing and treatment options in primary care relies on the development and implementation of patient-centred, collaborative models of care. In recent years there has been significant success in implementing nurse-coordinated or nurse-supported shared care programs for people with hepatitis C. In Western Australia, a nurse-supported shared care program for people with hepatitis C has operated in three regions for the last 10 years (WACHPR, 2014). In this model, patients are referred to a hepatitis nurse by a GP (or are self-referred). The hepatitis nurse then provides the patients with education about treatment options, completes initial pathology work-up and refers the patient to drug and alcohol or allied health services if needed. If the patient is a candidate for treatment and wishes to have therapy, the nurse refers the patient to a regional consultant physician. The nurse then co-ordinates the patient's treatment in consultation with the regional physician. Complex cases are referred to tertiary liver clinics.

An evaluation of the regional nurse-supported shared care program published in 2014 found that 98-100% of patients completed treatment and most patients were satisfied or very satisfied with the care they received (WACHPR, 2014). Benefits for patients included access to treatment closer to home, shorter waiting times, longer appointments, greater continuity of care and increased patient compliance (WACHPR, 2014). A number of other states have also developed

nurse-coordinated or nurse supported models of care with success. While a range of treatment options are needed, including tertiary liver clinics, our organisations believe that expanding nurse-coordinated or supported models of care would provide better access to treatment for patients with hepatitis C.

Rural and remote shared care hepatitis C treatment

A 2012 study reports an effective shared care hepatitis C treatment option in Western Australia (WA) utilising telehealth (Nazareth, 2013). The treatment involved a collaborative video-conferencing service model where rural and remote patients were reviewed and treated for hepatitis C by a hepatologist and nurse practitioner (NP). The study states that geographical location is a key barrier to Hepatitis C treatment uptake in WA as some people need to travel long distances to access treatment services resulting in *"...reduced medical supervision and treatment uptake"*. The aim of the study was to assess the feasibility of the telehealth mode of treatment delivery to remote patients with the hepatitis C virus. Of significance, the study trialled a shared care collaborative service model of independent, nurse-led clinics that included *"...therapy initiation, patient education and follow-up"*. The study reports that patients had an active role in the management and documentation of their treatment and general practitioners (GP) provided additional support as required. Adverse events were managed collaboratively by a hepatologist, NP and GP. Following treatment, patients were discharged to their GP. The study claimed to confirm *"...that telehealth is an effective option for the treatment of hepatitis C in rural and remote areas"* (Nazareth, 2013).

Reduce service fragmentation

Reducing service fragmentation within primary care and primary health care services would support greater access to hepatitis C services. Siloed service arrangements can pose a barrier to seeking and accessing timely hepatitis C assessment and treatment. For example, community mental health services often function as separate service entities to community drug and alcohol services, a lack of inter-service coordination can be a barrier to opportunistic interventions for hepatitis C diagnosis and treatment and also can be less economically efficient. Furthermore, continuity of care is challenging in some service arrangements where for example, clients of drug and alcohol services are treated for substance dependence and referred to other services for disease management. This can be problematic in the community context if there is no point of coordination for follow-up or where services are not co-located or arranged to support a smooth transition between service providers. The impact of better service integration should be examined to improve hepatitis C screening and treatment rates.

Testing and treatment options in acute care

Contact with acute care provides an opportunity to identify people with hepatitis C who may otherwise go undetected. Anecdotal evidence suggests that more advanced liver disease is being seen at the time of diagnosis. Routine screening and testing of 'at risk' groups, would help in the early identification of hepatitis C and potentially lead to improved treatment outcomes.

Testing and treatment options in Aboriginal Medical Services

Recommendation: *The goals of the Fourth National Hepatitis C Strategy 2014–2017 to improve the diagnosis and treatment of hepatitis C in Aboriginal and Torres Strait Islander people should continue to be supported.*

Our organisations note that while the Inquiry’s Terms of Reference include Aboriginal Medical Services (AMS), Aboriginal and Torres Strait Islander people access a wide range of health services, and some may never use an AMS. It is essential that the whole of the Australian health system is attuned to the needs of Aboriginal and Torres Strait Islander people accessing health care.

The *National Aboriginal and Torres Strait Islander Health Plan 2013–2023* envisions a health system that is free of racism and inequality, and which enables all Aboriginal and Torres Strait Islander people to gain access to health services that are effective, high-quality, culturally-safe and affordable (Australian Government, 2013). To achieve this vision, it is imperative that all health professionals understand the impact that past governmental policies and cultural practices have had on Australian’s First Nations People. It is equally important that policy makers and health professionals realise that Australia’s health system is not structured in a way that is conducive to comprehensive Aboriginal and Torres Strait Islander wellbeing. It is an individualised, medical-centric model, which poorly services the social and emotional wellbeing vital to the Aboriginal and Torres Strait Islander people’s communitarian, holistic health-centred culture. Culturally respectful practice by all health professionals is intrinsic to achieving better health outcomes for Aboriginal and Torres Strait Islander peoples, particularly when addressing sensitive issues such as hepatitis C.

Our organisations support the strategies outlined in the *Fourth National Hepatitis C Strategy 2014–2017* with regard to improving the diagnosis and treatment of hepatitis C in Aboriginal and Torres Strait Islander people, which are appropriately focused on the primary health care setting. We would also like to provide further comment on workforce development and partnerships with Aboriginal and Torres Strait Islander communities and health services.

Workforce development

The development of the health workforce is integral to achieving the *Fourth National Hepatitis C Strategy 2014–2017*. With institutional racism being a barrier to the recruitment and retention of Aboriginal and Torres Strait Islander people within the health system, and to the positive health outcomes of Aboriginal and Torres Strait Island peoples, an affirmative action approach should be adopted to increase the number of Aboriginal and Torres Strait Islander people working within the sector.

Furthermore, healthcare workers in primary health care and Aboriginal community-controlled services require appropriate knowledge and skills in sexual health, blood-borne virus prevention, treatment and care to support access to hepatitis C health care and treatment. Ensuring this specific professional development is available to health workers in these settings is integral to achieving positive health outcomes and to meeting the goals of the *Fourth National Hepatitis C Strategy 2014–2017*.

Establishing partnerships with Aboriginal community-controlled health services

Community control, engagement and partnership are key to achieving better health outcomes for Aboriginal and Torres Strait Islander people. Involving communities in the design, implementation and evaluation of new models of care will assist in the development of services that meet the needs of Aboriginal and Torres Strait Islander people.

Testing and treatment options in prisons

Recommendations:

- *Screening for hepatitis C should be routinely offered on entry and discharge from the custodial system with discharge screening linked to community-based management and treatment programs.*
- *When eligible, a person should receive and complete hepatitis C treatment while incarcerated whenever possible.*
- *Trials of needle and syringe exchange programmes in prisons should be supported nationally.*

There is a need to provide more comprehensive screening for hepatitis C for people in custody. The time that people spend in custodial settings is a valuable opportunity to assess prisoners' hepatitis C status, provide access to treatment for those who are willing and eligible for therapy. For some people, prison may be a time of relative stability in their lives, when they have access to health care and social supports that they may not be able to access in the community. Opportunities to complete hepatitis treatment while incarcerated should be made available wherever possible. Testing for hepatitis C can also improve the long-term health outcomes of people with hepatitis C by allowing for earlier advice about treatment options and referral where necessary. Testing raises awareness about hepatitis C transmission, provides an opportunity for education and may encourage people to modify risk behaviours. Screening for hepatitis C should be routinely offered on entry and exit from the custodial system. Where possible, exit screening should be linked to community-based management and treatment programs.

In addition to testing and treatment, it is important that prisons explore prevention and harm minimisation strategies to reduce the rate of new infections acquired in custody. The use of intravenous drugs remains common in Australian prisons and there is evidence to suggest that some people are initiated to intravenous drug use while in prison (Fetherston, 2013). Education about hepatitis C should be provided to all people in custody, as well as custodial personnel, to improve understanding of the prevention, transmission and management. While our organisations acknowledge that the provision of sterile injecting equipment is a complex issue, we support trials of needle and syringe exchange programmes in prisons as a harm minimization approach to intravenous drug use in prisons. The Public Health Association of Australia's report on the planned implementation of a needle and syringe program at a custodial centre in Canberra concluded that such programs, if implemented, could deliver significant health benefits to people in custody as well as staff and the broader community through the reduction in the transmission of blood borne viruses (Moore, 2011). Within the context of needle and syringe programs, the provision of safe injecting devices should be examined to minimise the risk of needle stick injuries to people in custody and custodial staff.

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

The costs of treating hepatitis C must be weighed against the economic, social and personal costs of the disease. People with hepatitis C are less likely to be engaged in the labour market (even when other social and demographic factors are controlled for) and are more likely to have a higher rate of absenteeism. They are also at risk of developing serious medical complications such as liver cirrhosis and cancer, requiring formal or informal care and are more likely to experience premature death. Thus, hepatitis C is costly to the individual and society (DAE, 2013). Studies have demonstrated that providing access to current treatments for both current and former injecting drug users is cost-effective and can be justified on economic grounds based on the number of quality-adjusted life years (QALYs) gained (Visconti, 2013).

Early treatment is significantly less expensive than treating the long-term consequences of hepatitis C. Economic modelling from 2004/5 showed that the annual unit cost of treating chronic hepatitis C with stage 0/1 liver disease was \$239, compared to \$78,639 to treat hepatitis C-related liver failure and \$118,146 to treat hepatitis C-related hepatocellular carcinoma (AE, 2005).

From a social justice perspective, it is important to note that the personal toll of hepatitis C overwhelmingly falls on disadvantaged groups, including incarcerated women and Aboriginal and Torres Strait Islander people. Failing to address the low levels of treatment for hepatitis C undermines Australia's efforts to improve equity within the community and 'close the gap' with regard to Aboriginal and Torres Strait Islander health outcomes.

It is also important to acknowledge that new, cost effective models of care are being developed. If expanded, these new models will enable more people to access hepatitis C treatments at lower unit cost. Broad investment in cost-effective early treatment strategies has the potential to increase access to hepatitis C treatment and to improve health outcomes.

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

The *Economic Evaluation of the Hepatitis C in Australia* report prepared in 2005 for the Australian Government Department of Health and Ageing concluded that "...there are significant returns available from investment in hepatitis C education, prevention and harm minimisation programs". In Australia, most new hepatitis C infections are related to the sharing of injecting equipment. As long as new infections of hepatitis C continue to occur, education, prevention efforts and harm minimisation must be strengthened and remain targeted towards people who inject drugs. Methods to improve the prevention of new hepatitis C infections should include:

- The provision of needle syringe programs and the availability of supervised injecting rooms for injecting drug users.
- Education and behaviour management programs, including access to treatment programs (such as opioid withdrawal or methadone maintenance programs) for injecting drug users.
- Harm minimisation programs and policies for injecting drug users in custodial settings and the provision of education to custodial staff to promote awareness, tolerance and safety.
- Targeted programs for Aboriginal and Torres Strait Islander communities through the provision of culturally relevant educational resources and easy access to appropriate and culturally respectful services

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