NSW HEPATITIS C STRATEGY
2014-2020

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SHPN: (CPH) 140242
ISBN: 978-1-74187-048-0

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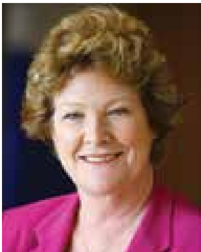
2014

FOREWORD

HEPATITIS C IS A SIGNIFICANT HEALTH ISSUE, WITH AN ESTIMATED 90,000 NSW RESIDENTS LIVING WITH CHRONIC HEPATITIS C.



NSW Health, in partnership with health and welfare services, non-government organisations, researchers and affected communities are doing a tremendous amount of work to reduce the burden of hepatitis C in NSW. Together we have made significant progress. We have prevented many hepatitis C infections from occurring through the availability of sterile injecting equipment, our safe blood supply, and other harm reduction activities. Our investment in the Needle and Syringe Program (NSP) is highly cost effective – for every $1 invested in the NSP, $4 is returned in direct health savings.

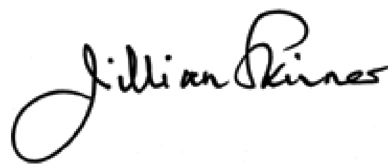
Nevertheless, there are nearly 10 hepatitis C infections reported every day in NSW. While most of these infections are likely to have been acquired some time before, new infections still occur and more needs to be done to increase our prevention efforts. Similarly, we need to do more to treat people living with hepatitis C. In NSW, the number of people with chronic infection is large and growing, as is the burden of liver disease, cirrhosis and liver cancer associated with chronic hepatitis C. Health services will need to adapt and innovate if we are to effectively address the growing burden of hepatitis C in NSW.

Effective hepatitis C treatments are available, and recent breakthroughs mean that even safer and more effective treatments are likely to be available soon. Our challenge will be to ensure these new treatments are made widely available while ensuring that current treatments are available to those who need them now.

Primary care services and nurse-led models of care will be at the forefront of efforts to expand treatment – connecting patients in primary health settings with specialist centres – and will continue to support people with chronic hepatitis C to effectively manage their infection.

This *Strategy* has an equity focus. It requires the public health system to prioritise work with groups and in settings where hepatitis C is most prevalent, so that we can direct focus to those with the greatest need. Our successes to date and the international evidence shows that services should be actively reaching into correctional facilities, drug and alcohol services, mental health services, Aboriginal Community Controlled Health Services and other primary care settings to provide treatment and implement prevention strategies.

Finally, we have seen that real and perceived stigma and discrimination toward people with or at risk of hepatitis C hampers our efforts to prevent hepatitis C and provide health care. Unlawful discrimination should not be tolerated in the health system, and we will work with community organisations to ensure people are aware of their right to care without discrimination.



Jillian Skinner MP
Minister for Health
Minister for Medical Research

STRATEGY AT A GLANCE

GOALS

TO REDUCE HEPATITIS C INFECTIONS IN NSW

TO IMPROVE THE HEALTH OUTCOMES OF **PEOPLE LIVING WITH HEPATITIS C** IN NSW

TARGETS

REDUCE SHARING OF **INJECTING EQUIPMENT** AMONG PEOPLE WHO INJECT DRUGS **BY 25%**

INCREASE THE NUMBER OF PEOPLE **ACCESSING HEPATITIS C TREATMENT** IN NSW **BY 100%***

** Over the life of this Strategy, a range of new drugs may become available that will change treatment and service delivery options. This target is subject to change accordingly.*

ACTIONS

PREVENT: Build on established hepatitis C prevention efforts	MANAGE: Better management of hepatitis C	TREAT: Improve access to hepatitis C treatment
• Ensure the Needle and Syringe Program is meeting the needs of at-risk populations • Continue to implement, and look for opportunities to enhance, drug and alcohol services and drug diversion programs • Explore the use of notifications to better understand transmission, identify and investigate clusters and implement public health control measures where feasible • Implement and evaluate other evidence-based prevention strategies	• Increase primary care, Aboriginal Community Controlled Health Services, correctional facilities and drug and alcohol treatment services offering testing, clinical management, treatment assessment and follow up among people from priority populations • Support best practice management of hepatitis C and its complications • Implement programs that support people to effectively manage their condition	• Expand the number and types of services able to provide hepatitis C treatment • Increase the proportion of clients treated through nurse-led and primary care models • Prepare to deliver new hepatitis C treatment regimens on an expanded scale • Support participation in clinical trials

SYSTEM ENABLERS

- Surveillance
- Performance monitoring and evaluation
- Clinical redesign and innovation
- Health systems and policy relevant research
- Workforce development
- Cultural competence
- Community engagement and partnerships
- Effective governance
- An evidence-informed population health approach

PRIORITY POPULATIONS

- People living with hepatitis C
- People who inject drugs, especially new initiates
- People in or recently in custodial settings
- Aboriginal people
- People from culturally and linguistically diverse backgrounds
- Young people who are at risk of injecting

A key part of the Strategy is to increase the number of patients treated with antiviral drugs. Currently the approved therapies are limited due to side effects and the relative long duration of treatment of 6 to 12 months. This limits treatment if there are medical co-morbidities such as advanced liver disease and liver failure. However, over the duration of the strategy we will see the introduction of oral antivirals, taken once a day with minimal side effects, for 8 to 12 weeks with a cure rate of greater than 95%. I have already seen patients in clinical trials for these drugs who are on the verge of requiring liver transplantation have their disease progression stopped with rapid eradication and cure of the hepatitis C virus. Thus, dramatic changes in treatment outcomes should occur over the time of the Strategy. Challenges will remain in expanding treatment to all patient groups at low cost, using therapies to prevent transmission and managing liver co-morbidities related to disease progression such as alcohol use, diabetes and obesity. Despite these challenges, the future of treatment for hepatitis C is about to undergo a revolution with high viral cure and amazing outcomes for persons who have been infected.

Dr Geoff McCaughan
Director A.W Morrow GE/Liver Centre and Liver Transplant Unit, Royal Prince Alfred Hospital; Centenary Research Institute, University of Sydney

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WHY A STRATEGY FOR HEPATITIS C?

Hepatitis C is a blood-borne virus that affects the liver. Transmission occurs when blood containing the virus enters the bloodstream of another person. In Australia, the major mode of transmission of hepatitis C is through sharing or re-using injecting equipment which has been contaminated by infected blood. A number of people from culturally and linguistically diverse backgrounds acquire hepatitis C through unsterile medical procedures overseas. Transmission is less likely but can also occur through: unsterile tattooing and body piercing procedures; being born to a mother who has hepatitis C; transfusion of blood products prior to 1990 (when screening of donated blood began); needle-stick injuries in health care settings; and during sex where blood is present.[1]

On average, one in four people who contract hepatitis C will clear the virus spontaneously without intervention within six months of acquiring the infection; while the remaining three will develop chronic hepatitis C. In Australia in 2012, an estimated 310,000 people had been infected with hepatitis C, about 230,000 of whom had a chronic infection.[2]

About 90% of new hepatitis C infections are attributable to injecting drug use with unsterile injecting equipment.[1] In Australia, research suggests that the number of new infections occurring each year has declined steadily since 2003.[2,3] This reduction has been attributed to factors such as changes in the Australian drug market, improved access to opioid substitution therapy and increased investment in NSPs.[3,4] Nevertheless, the number of new hepatitis C infections occurring each year in NSW remains unacceptably high.[5] This underscores a need to bolster hepatitis C prevention efforts in NSW.

Among people who inject drugs, the risk of acquiring hepatitis C is particularly high in the first few years following initiation of injecting.[6] The median age at initiating injecting drug use is 18 years.[7] Young people and new initiates are therefore priority groups for hepatitis C prevention. Several other sub-populations are disproportionately affected by hepatitis C, with levels of disease higher among people originating from high prevalence countries, people in custodial settings and Aboriginal people.[1,8,9] Additionally, the problem of HIV and hepatitis C co-infection, especially among men who have sex with men, is being increasingly recognised.

3 OUT OF **4** PEOPLE WILL DEVELOP **CHRONIC HEPATITIS C** FOLLOWING INFECTION

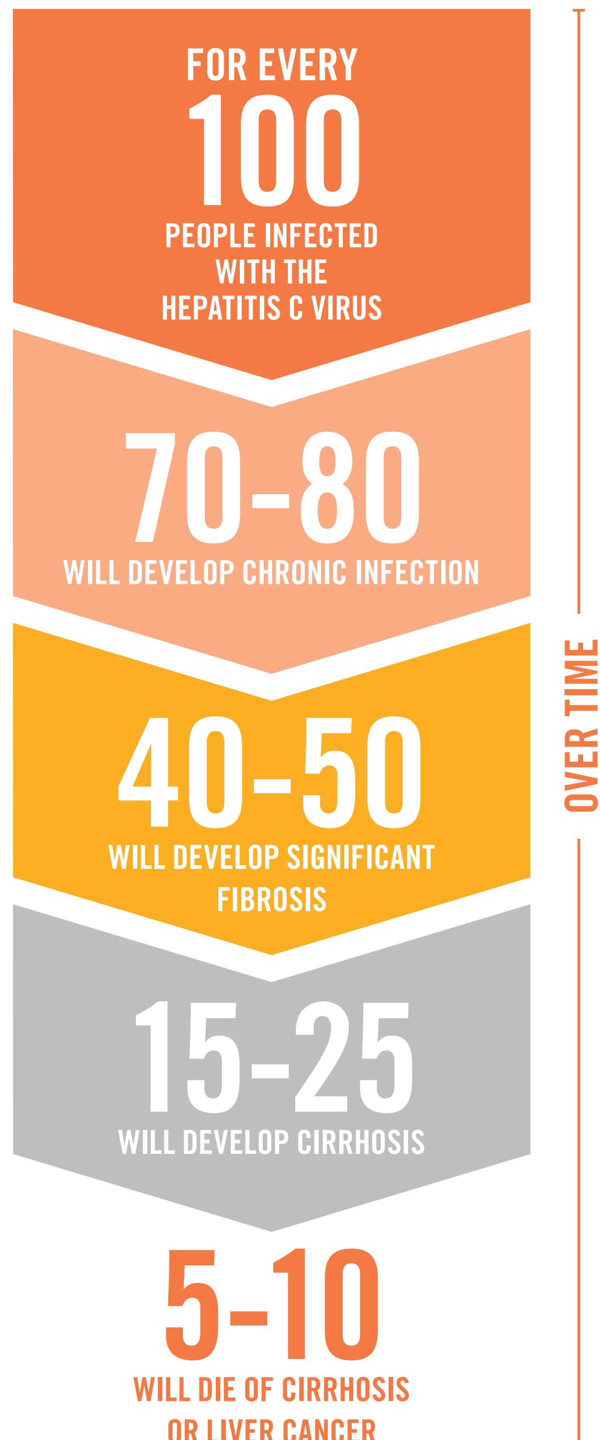
HEALTH IMPACT OF HEPATITIS C

Most people do not experience any symptoms of hepatitis C for some time after infection. However, hepatitis C causes inflammation of the liver, which over time can lead to cirrhosis (scarring of the liver tissue). In Australia, an estimated 15,000 people have hepatitis C-related cirrhosis.[10] Cirrhosis undermines the normal functioning of the liver and can lead to complications, such as liver failure, internal bleeding and liver cancer.

In developed countries like Australia, hepatitis C is a major risk factor for primary liver cancer.[11] Survival rates for this type of cancer are poor, with only 15% of those diagnosed living at least five years beyond the initial diagnosis.[11] In NSW, between 2000 and 2009, the age-standardised rate of liver cancer increased from 4.0 to 6.6 per 100,000 persons, with 507 cases recorded in 2009.[12] Additionally, the personal and community costs associated with hepatitis C are large.[11,13-15] For example, hepatitis C is the single biggest driver of demand for liver transplantation in Australia.[16]

Many people with chronic hepatitis C have other health problems that can worsen their condition and accelerate liver disease progression. Examples include hepatitis B, HIV, obesity, diabetes and excessive alcohol consumption.[17-19] Many of these co-morbidities are preventable and people with hepatitis C should be supported to adopt behaviours that enhance general health and wellbeing.

PROGRESSION OF HEPATITIS C



NEW TREATMENTS – NEW OPPORTUNITIES

There are treatments that can cure hepatitis C in 70-80% of cases, but only about 2% of people with hepatitis C start treatment in any year.[20] Factors that influence the uptake of current treatments include their tolerability and duration, lack of awareness about their availability and effectiveness, as well as barriers to accessing treatment services in some areas.[21]

In addition, the promise of better treatments on the horizon has led many to delay starting therapy. Over the life of this *Strategy*, new interferon-free treatments will be available that have cure rates of above 90%, simplified dosing schedules and reduced side effects.[20,22] However, waiting for better treatments is not an option for everyone. Some people's clinical condition will require them to start treatment sooner rather than later, so this *Strategy* places an emphasis on monitoring the liver health of people with hepatitis C to inform treatment decisions to prevent severe liver damage and cancer.

As treatment continues to improve, there will likely be a significant increase in demand for hepatitis C services. Therefore, planning needs to commence now to ensure we have models of care that support improved access, from testing through to treatment. A major focus of this *Strategy* is to monitor and manage more disease in general practice, correctional facilities, Aboriginal Community Controlled Health Services, drug and alcohol services, mental health and youth health services.

“While hepatitis C infection rates in NSW have decreased since 2000, reducing these further remains a challenge. Ensuring that integrated hepatitis C prevention and treatment measures reach those most vulnerable will be central to achieving this. Services need to be accessible and acceptable to key populations, including people who inject drugs and young people at risk of injecting. Additional measures will be needed to reach doubly marginalised populations, such as Aboriginal and homeless people affected by hepatitis C, who have traditionally had poor access to health care. Overcoming barriers to care, particularly stigma and discrimination, will also be crucial. Services working together will achieve this.”

Dr Ingrid van Beek AM
Director, Kirketon Road Centre, South Eastern Sydney Local Health District

GOALS AND TARGETS

The goals of this *Strategy* are to:

- Reduce hepatitis C infections in NSW; and
- Improve the health outcomes of people living with hepatitis C in NSW.

To achieve our goals, our program efforts will focus on:

- Reducing sharing of injecting equipment among people who inject drugs by 25%; and
- Increasing the number of people accessing hepatitis C treatment in NSW by 100%.

Over the life of this *Strategy*, new interferon-free treatments will likely become available in Australia. If this happens, and depending on the affordability and accessibility of these new regimens, it should be possible to treat considerably more people in NSW, and our treatment target will be adjusted accordingly.

PRIORITY POPULATIONS

This *Strategy* focuses our efforts on working with those groups of people that are most at risk or most affected by hepatitis C. These 'priority populations' are:

- People living with hepatitis C;
- People who inject drugs, especially new initiates;
- People in or recently in custodial settings;
- Aboriginal people;
- People from culturally and linguistically diverse backgrounds; and
- Young people who are at risk of injecting.

OUR VALUES

NSW Health's core values are collaboration, openness, respect and empowerment.

Everyone has the right to be treated with dignity and respect in their interactions with health services. This is central to our efforts to improve the health and wellbeing of priority populations in this *Strategy*. Unfortunately, shame and stigma associated with injecting illicit drugs can act as barriers to health services for people living with hepatitis C.[23] These issues are confounded by the barriers already experienced by people who are Aboriginal, from culturally and linguistically diverse backgrounds, or facing health and social disadvantage.

Therefore, programs and policies that underpin respectful service delivery to people who have injected drugs or live with hepatitis C will be required over the life of this *Strategy*.

To ensure NSW Health services are delivered equitably to those most in need of receiving appropriate care, the proportion of hepatitis C services provided to priority populations identified in this *Strategy* will, where possible, be reported. While there is no routinely collected data on stigma or discrimination related to hepatitis C specifically, overall performance of the health service in providing care in line with our values is captured in the NSW Health Patient Survey Program, particularly in relation to 'respect', 'dignity', 'politeness' and 'courtesy'.

“Despite recent advances in direct acting antiviral therapies, and the potential impact of these new treatments on hepatitis C incidence, financial and other barriers to access mean that uptake by people who inject drugs will likely remain low in the medium term. Therefore, a continued focus on evidence-based and cost effective prevention remains imperative. By supporting initiatives designed to increase access to sterile injecting equipment, reduce receptive syringe sharing and increase opioid substitution therapy coverage, this Strategy has the potential to reduce the number of people who acquire hepatitis C in NSW. Our recent research adds weight to opioid substitution therapy as a hepatitis C prevention measure. HITS-c is the first study to observe an independent protective effect of opioid substitution therapy against hepatitis C infection among people who inject drugs.”

Professor Lisa Maher
Head, Viral Hepatitis Epidemiology and Prevention Program
NHMRC Senior Research Fellow, The Kirby Institute, UNSW Australia

PRIORITY 1: BUILD ON ESTABLISHED HEPATITIS C PREVENTION EFFORTS

HARM REDUCTION

Access to sterile injecting equipment and drug treatment programs are proven, cost-effective ways to prevent hepatitis C transmission.[4,24,25] A continued harm reduction approach, combined with other complementary prevention strategies, is central to prevention efforts to further reduce the number of new infections each year.[26]

Among people attending the NSW NSP in 2013, a concerning proportion (20%) reported sharing injecting equipment over a four week period.[27] The reported rate of sharing injecting equipment among NSP attendees in 2014 has decreased to 13%.[28] Findings from the 2015 data collection will indicate whether the decrease is a continuing trend, however the high proportion of those reporting having shared injecting equipment suggests that sterile equipment is not always available when and where it is needed, even among people already accessing the NSP. Other factors including co-morbidities and individual, social, and structural factors can also contribute to the reuse of equipment.[29] This signals a need to improve the NSP by increasing the number of access points, extending hours of service and diversifying the ways in which sterile injecting equipment is made available. The program should also be responsive to changing drug use patterns, such as the increase in injecting of methamphetamine and performance and image enhancing drugs, and consider the implications of these trends for hepatitis C transmission. Therefore, NSPs need to be flexible and targeted, ensuring that sterile injecting equipment is readily available in the areas of highest need and for those most at risk, such as Aboriginal people, street-based injectors, people from culturally and linguistically diverse backgrounds, people recently incarcerated and young people.

In addition, given the high levels of trust placed in NSP services by their clients,[29] NSPs are ideal sites in which other health services can be delivered. Such an approach can be effective in meeting the sometimes complex health needs of people who inject drugs and contribute to lowering rates of reuse and sharing of injecting equipment. Importantly, NSP services should be designed, delivered and evaluated in line with the *NSW Needle and Syringe Program Guidelines 2013*.

It is essential that the NSP is complemented by other initiatives, such as drug and alcohol treatment programs like opioid substitution therapy, that reduce injecting risk behaviour.[26] Individuals can face a number of barriers in initiating or continuing opioid substitution therapy, such as financial and geographical barriers. People who inject drugs, especially those who are receiving opioid substitution therapy, have a mental illness, or are homeless, should be supported to access other health services and agencies as required and be educated about safer using practices.

There is a high prevalence of hepatitis C among prisoners and an over representation of people who inject drugs and Aboriginal people in correctional facilities.[8,30] There is therefore a need to strengthen existing harm reduction strategies in prisons, such as opioid substitution therapy, and to support inmates to adopt safe behaviours. Additionally, as people are released and transition back to the community they should be assisted to connect with health and relevant social services.

SURVEILLANCE OF HEPATITIS C

Gathering additional information about hepatitis C notifications will help explain the circumstances in which hepatitis C was acquired. This information can help elucidate what can be done in the future to avoid similar transmissions occurring. Over the life of this *Strategy*, methods to better detect newly acquired infections and clusters will be explored. Such methods may include targeted follow up of notifications. A range of options will be investigated to determine which are likely to be most effective and feasible, such as targeting notifications in young people (aged between 15 and 19 years), people that have been tested/ screened due to high risk behaviours, and people with very high alanine aminotransferase (a sign of acute liver damage). We will also explore the feasibility of using laboratory information systems to identify people who have been infected recently. Additionally, we will support diagnosing clinicians to strengthen patient follow-up, including the provision of education and appropriate referrals, and contact tracing.

ADDITIONAL PREVENTION STRATEGIES

Better awareness of hepatitis C is needed. This will require tailored prevention, community mobilisation and education programs among people who inject drugs, young people, prisoners, Aboriginal people and people from culturally and linguistically diverse backgrounds. To be most effective, these programs should be coordinated with other harm reduction, care and treatment services.[26] Given the paucity of evidence about interventions to reduce risk behaviours and hepatitis C transmission,[31] education and behavioural programs should be well designed and evaluated. The sexual transmission of hepatitis C among HIV positive men who have sex with men is increasingly recognised as a challenge for prevention.[32] More effort is needed in reducing the risk of sexually acquired hepatitis C infection in this sub-population.

Unsterile skin penetration procedures are a risk for infection with blood borne viruses. In NSW, premises that perform skin penetration procedures (such as tattooing, acupuncture, ear piercing, some nail treatments and hair removal) have infection control responsibilities, as described in the *Public Health Act 2010* and *Public Health Regulation 2012.* Public Health Units in Local Health Districts and local councils have a role in monitoring adherence to these infection control requirements, with environmental health officers having the power to issue improvement notices and prohibition orders to non-complying premises. Additionally, health promotion approaches will be important in preventing risk behaviours associated with home tattooing and similar unregulated skin penetration procedures.

This *Strategy* recognises the role of laws and law enforcement practices in contributing to an environment that supports public health. The NSP, opioid substitution programs and other hepatitis C prevention programs for people who inject drugs will be most effective when they are implemented in a supportive legal and policy environment. Harm reduction must remain explicitly stated as National and State policy and be practically supported, or people may be deterred from health services.

> **“The social position of injecting drug use means that Needle and Syringe Program clients often experience negative judgements when seeking health care. As a result, these clients can become mistrustful of mainstream health services and choose to avoid such services. In comparison, the high level of trust placed in Needle and Syringe Programs by clients is a key resource yet to be harnessed in the hepatitis C sector. Needle and Syringe Programs could become the site to host services to address hepatitis C, including referrals, testing for, monitoring and treating the infection, and to address other key health and social issues which are important to people who inject drugs.”**

Professor Carla Treloar
Deputy Director, Centre for Social Research in Health, UNSW Australia

ACTIONS

Harm reduction

- Ministry of Health to establish a multidisciplinary NSP planning network to guide service improvement.

  Partners: Police, Corrective Services NSW, Justice Health and Forensic Mental Health Network, non-government organisations, researchers and affected communities.

- Pharmacy Guild to improve the efficiency and effectiveness of the NSW Pharmacy Fitpack Scheme and opioid substitution services.

  Partners: Local Heath Districts and Ministry of Health.

- Local Health Districts to improve the efficiency and effectiveness of their NSPs.

  Partners: Ministry of Health, Aboriginal Community Controlled Health Services, non-government organisations and affected communities.

- Ministry of Health to finalise a pilot project underway exploring the effectiveness, risks and benefits of enabling people who inject drugs to collect and distribute sterile injecting equipment to their peers, and to roll out the project in line with recommendations from its evaluation.

  Partners: NUAA and researchers.

- Justice Health and Forensic Mental Health Network and Corrective Services NSW to strengthen existing harm reduction efforts in correctional facilities and continue to support inmates as they transition back to the community.

  Partners: Ministry of Health, NUAA, researchers and affected communities.

- Local Health Districts, Justice Health and Forensic Mental Health Network and Corrective Services NSW to continue to implement and look for opportunities to enhance drug and alcohol treatment, including opioid substitution therapy.

  Partner: Ministry of Health.

- Local Health Districts to strengthen relationships between the NSP and a range of health and social services to improve the accessibility and continuity of health care for NSP clients and to promote harm reduction approaches across NSW Health and in other relevant organisations.

  Partners: Ministry of Health and non-government organisations.

Surveillance of hepatitis C

- Health Protection NSW to investigate opportunities to better detect newly acquired hepatitis C notifications and so improve the prevention response, by improving recording of demographic information, identifying more detailed risk factors for transmission, and identifying clusters.

  Partners: Ministry of Health, Local Health District Public Health Units and researchers.

- Ministry of Health to investigate ways to prompt appropriate education, care, referral, testing and contact tracing by diagnosing clinicians.

  Partners: Health Protection NSW, general practitioner organisations, non-government organisations, Local Health Districts, and Aboriginal Community Controlled Health Services.

Other public health strategies

- Health Protection NSW to support Local Health Districts, local councils and professional bodies in providing educational resources and training to staff and skin penetration practitioners on 'Infection control for the skin penetration industry' and to monitor skin penetration premises for compliance with the *Public Health Regulation 2012.*

  Partners: Local government and Local Health Districts.

- Non-government organisations and affected communities to lead community mobilisation efforts for people at risk of hepatitis C.

- Key stakeholders to implement and evaluate integrated health promotion and education strategies, including peer-led approaches and strategies to reduce risk behaviours associated with unregulated skin penetration procedures.

  Partners: Ministry of Health, Local Health Districts, Aboriginal Health and Medical Research Council, non-government organisations, Multicultural HIV and Hepatitis Service, affected communities and researchers.

- Local Health Districts to promote policies and practices that reduce stigma and discrimination in health-care settings.

  Partners: non-government organisations, Ministry of Health and affected communities.

- Ministry of Health to work collaboratively with NSW Department of Education and Communities to strengthen school-based health promotion programs to prevent blood-borne infections.

  Partners: non-government organisations, Local Health Districts, and NSW secondary schools.

- Ministry of Health to implement integrated and targeted social marketing campaigns which promote hepatitis C prevention and reduce hepatitis C-related stigma and discrimination in the community.

  Partners: non-government organisations and Australian Government.

“In 1994 I was diagnosed with hepatitis C and felt devastated. I disclosed to my Nurse Unit Manager and was told to keep it a secret, beginning 14 years of fear and depression. In 2008 after 48 weeks' difficult treatment, I was cured. I was hospitalised often during treatment, and was hurt by the attitudes of some medical staff. Today I speak out against these attitudes because I feel, as a health care worker, and as an Aboriginal woman, in order to receive the right health care it should not matter how someone contracted hep C.”

Ms Kerri-Anne Smith
C-een & Heard Speaker for Hepatitis NSW,
Member of the Hepatitis NSW Board of Governance

PRIORITY 2: BETTER MANAGEMENT OF HEPATITIS C

TESTING, DIAGNOSIS AND MONITORING

Australia is recognised as having a relatively small proportion of undiagnosed hepatitis C infections, with an estimated 85% of all cases identified.[1] However, hepatitis C infections are usually asymptomatic at first, and many people with hepatitis C are not diagnosed until some years after they acquired the infection. Timely testing and diagnosis of people at risk of hepatitis C, complemented with appropriate education, referral and care can reduce the number of people living with hepatitis C progressing to advanced liver disease. People who know they have hepatitis C may be more likely to make healthy lifestyle choices, consider treatment and take steps to prevent transmission to others.[33] However, evidence suggests that testing procedures in NSW require improvement, with people who inject drugs offered the least information and referral following diagnosis.[34]

Hepatits C prevalence is estimated to be high in some migrant groups, including Egyptian and Chinese Australians,[35] and strategies to improve testing in these groups are needed.

Among HIV positive men who have sex with men, who are already having regular blood tests at health services, it may be possible to identify and treat more acute cases of hepatitis C.[36,37]

Pregnant women need to be screened for risk factors for hepatitis C, and tested when appropriate. Pregnant women who are hepatitis C positive and their babies should be referred to appropriate health services.

Supporting primary care providers to identify risk factors that should prompt testing may assist in achieving earlier diagnosis and a reduction in the numbers of those who are yet to be diagnosed.

New testing technologies and approaches will be explored that can contribute to further reducing the pool of undiagnosed hepatitis C infections in NSW.

MONITORING LIVER HEALTH

All people with hepatitis C should be regularly monitored by a medical practitioner, regardless of their treatment intentions, to see how their disease is progressing and discuss developments in treatment. There are both non-invasive (transient elastography or ultrasound) and biological (blood test algorithms) methods of assessing fibrosis and liver health among people living with hepatitis C.[38-40] Advanced or advancing fibrosis will warrant serious treatment contemplation.

People with cirrhosis, regardless of whether they have ever been treated for hepatitis C, should be seen more regularly for liver cancer screening through a blood test and liver ultrasound. Delayed diagnosis of liver cancer can have devastating outcomes and regular screening in people with cirrhosis can lead to early detection of tumours and better survival.[41,42]

Nurses working with the hepatitis C affected community require a broad range of skills to enable them to offer management, care and support to this population, particularly in rural and regional areas with decreased access to primary health care and specialist services. Nurses liaise with a range of health care providers including GPs, drug and alcohol services and Aboriginal health workers to increase access to services across the community. Recognition of the nurse's role by expansion of nurse-led clinics in a variety of settings and coordination of services through primary health will increase treatment access in the future.

Tracey Jones MNurs(NP) RN
Hepatology Nurse Practitioner, Viral Hepatitis Service,
Department of Gastroenterology, John Hunter Hospital
HNELHD Conjoint Lecturer, University of Newcastle

A/Prof Adrian Dunlop
Area Director, Drug & Alcohol Clinical Services,
HNELHD Senior Lecturer, School of Medicine & Public Health, University of Newcastle

PEOPLE WITH HEPATITIS C
SHOULD BE MONITORED EVERY
6-12 MONTHS
BY A MEDICAL PRACTITIONER

MANAGING CARE IN THE COMMUNITY

At present, not enough people are having their hepatitis C regularly monitored and, of those that are, a large number are seen in specialist public services. Given improvements in the understanding of hepatitis C, improvements in treatment and the sheer number of people requiring monitoring, it will be necessary over the life of this *Strategy* to build the capacity of primary health care and other community-based health services to monitor and manage people living with hepatitis C. This will free up specialist public liver clinics to focus on:

- Seeing people most in need of specialist attention, such as those with advanced liver disease or other complex health or support issues; and
- Building the capacity of primary health care and other community-based health services to integrate monitoring and management into the care of patients with hepatitis C.

PROGRAMS TO SUPPORT PEOPLE TO MANAGE THEIR HEALTH

Priority populations need to increase their knowledge of hepatitis C and its management. Primary care providers, community-based organisations and people living with hepatitis C are well placed to provide information, education and support to people who are newly diagnosed about treatment and risk factors for fibrosis progression, such as obesity, diabetes, alcohol consumption, marijuana use, prolonged infection and immunosuppression. Interventions to support people with hepatitis C to reduce their risk of liver disease progression should be evidence based, developed with the participation of at risk communities and carefully evaluated. Additionally, it is particularly important that such interventions and programs reach people with one or more of the following co-morbidities: cirrhosis; fatty liver disease (alcohol and non-alcoholic fatty liver disease); hepatitis B; HIV; obesity; dependence on alcohol or marijuana; an immunosuppressive condition; diabetes; or a mental illness.

ACTIONS

Primary health care

- Ministry of Health and Local Health Districts to support general practitioners, nurses, and other primary care providers to adopt best practice hepatitis C identification, assessment, disease monitoring, management (including co-morbidities) and referrals.

  Partners: general practice organisations, Health Protection NSW, the Aboriginal Health and Medical Research Council, Aboriginal Community Controlled Health Services, drug and alcohol services, mental health services, sexual health clinics, Justice Health and Forensic Mental Health Network and non-government organisations.

Strengthening the health system focus on hepatitis C management

- Local Health Districts to implement policies and practices that reduce stigma and discrimination in health care services.

  Partners: non-government organisations, researchers, and Ministry of Health.

- Ministry of Health and Local Health Districts to improve access to services providing hepatitis C monitoring and management.

  Partners: general practice organisations, Aboriginal Community Controlled Health Services, drug and alcohol services, mental health services, Local Health Districts, Agency for Clinical Innovation, Justice Health and Forensic Mental Health Network and paediatric services.

- Ministry of Health and Agency for Clinical Innovation to monitor the effectiveness, including cost effectiveness, of methods to improve liver cancer screening among people with cirrhosis.
- Ministry of Health and Agency for Clinical Innovation to monitor the evidence relating to, as well as the feasibility of, point of care testing for hepatitis C.
- Ministry of Health to implement targeted strategies to further reduce undiagnosed hepatitis C infections.

  Partners: general practice organisations, non-government organisations, Aboriginal Community Controlled Health Services, drug and alcohol services, mental health services, sexual health clinics and Justice Health and Forensic Mental Health Network, Multicultural HIV and Hepatitis Service, and NSW Refugee Health Service.

- Ministry of Health to work with the Australian Government to ensure that liver disease is included in the broader chronic disease management agenda.

Community focussed actions

- Non-government organisations and affected communities to lead community mobilisation efforts for people living with hepatitis C.
- Local Health Districts and non-government organisations to implement and evaluate programs that support patient self-management, including changes to diet, exercise and alcohol intake, among people living with hepatitis C.

  Partners: general practice organisations, Aboriginal Community Controlled Health Services and Multicultural HIV and Hepatitis Service.
- Local Health Districts to implement and evaluate models of peer-based support and education which support patient self-management in people with hepatitis C.

  Partners: non-government organisations, Multicultural HIV and Hepatitis Service and affected communities.

The era of new hepatitis C treatment, particularly interferon-free direct acting antiviral regimens, has the potential to empower both people living with hepatitis C and health care professionals. Strategies to optimise this potential are urgently required, including enhanced hepatitis C service delivery through primary care, drug dependency treatment, prison, and Aboriginal medical service settings. Investment in primary care practitioner hepatitis C treatment education and training and removal of regulatory barriers to prescribing are essential.

Professor Greg Dore
Head, Viral Hepatitis Clinical Research Program, Kirby Institute, UNSW Australia

Dr Penny Abbott
GP, Aboriginal Medical Services

PRIORITY 3: IMPROVE ACCESS TO HEPATITIS C TREATMENT

PREPARING FOR NEW TREATMENT REGIMENS

It is expected that when interferon-free treatments become available, demand for treatment will increase. However, it is possible that the prescription of new treatments under the Pharmaceutical Benefits Scheme (PBS) will be limited to specialists only or to patients with advanced liver disease. Planning for the implementation of new treatment regimens within these uncertain parameters poses challenges for NSW as to how it will best maximise treatment accessibility, infrastructure and options for people living with hepatitis C.[20]

For those who require treatment now or do not want to wait for new treatments, which could be years away, there will need to be a continued focus on making it easier to access current treatment options. This will require up-skilling the drug and alcohol, Justice Health and Forensic Mental Health Network, sexual health and primary care workforce to effectively assess people living with hepatitis C, advise them about treatment options and to work with patients through their treatment journey. NSW Health supports current and future efforts to maximise the accessibility of interferon-free treatments – once these are approved for supply in Australia. In the meantime, when the opportunity arises, clinicians in NSW should support eligible and suitable patients to access new treatments through clinical trials.

MAKING IT EASIER TO GET TREATED

Treatments for hepatitis C are available that will successfully clear the virus in the majority of patients. Unless the numbers of patients accessing this treatment significantly increases, the future burden of hepatitis C-related disease will continue to be substantial.[15] Given the approaching era of highly effective, simple and tolerable hepatitis C treatments, and high prevalence among drug injecting populations, research is increasingly heralding treatment not only as a way to reduce morbidity associated with hepatitis C, but as a prevention method among people who inject drugs.[43-46]

At present, treatment is only subsidised under the PBS when it is prescribed by a specialist medical practitioner, or by a limited number of general practitioners who are accredited to prescribe treatment in a shared-care arrangement with a specialist. As a result, treatment is predominantly provided in public tertiary specialist settings, or by specialist visits to outreach sites. This service model has limited capacity to halt the foreshadowed burden of liver disease or meet the expected treatment demand. For people living in rural and regional NSW, specialist hepatitis C doctors are not geographically close and in some cases there are waiting periods. In addition to these supply restrictions, demand for treatment has been low among people living with hepatitis C

because of the promise of interferon-free treatments in the near future, owing to their reduced toxicity and simpler dosing schedules.[20,47]

There is a need for more people with hepatitis C to commence treatment if we are to reduce the growing burden of liver disease. The service design in clinical settings could also be examined for efficiencies – ensuring specialist management is preserved for complex patients and clinical review. The simpler nature of new treatments may facilitate changed service delivery in specialist centres and allow easier integration of treatment services in other settings, supported by outreach services and/or telemedicine.

In recent years, NSW Health has been piloting a range of alternative treatment models in preparation for expanded treatment, predominantly through hepatitis C nurses working in primary care settings, correctional facilities and drug and alcohol clinics.[48,49] Under this *Strategy*, the lessons from these pilots will be consolidated and successful models scaled up.

NURSE LED TREATMENT

A Ministry of Health funded pilot of hepatitis C treatment in NSW correctional facilities demonstrated the feasibility and efficiencies of a nurse-led model. Despite a high proportion of individuals who reported current illicit drug use or had a psychiatric disorder(s), almost 80% of patients were able to commence treatment with phone or teleconference involvement by specialists. Treatment success rate and safety was comparable to that in specialist settings.[48] Nurse-led treatment should continue to be used in correctional facilities, and extended to community and outreach settings which some services are already using. Effective implementation requires comprehensive training and ongoing support for participating nurses.

ALMOST 80%
OF PATIENTS WERE ABLE TO
COMMENCE TREATMENT
WITH PHONE OR TELECONFERENCE
INVOLVEMENT FROM A SPECIALIST

Justice Health & Forensic Mental Health Network has built upon the successful pilot of the nurse-led model of assessment and treatment for patients with chronic hepatitis C, and has now implemented the model in 15 custodial centres across the state. With detailed protocols to guide the assessment and treatment pathway, access to fibro-elastography, suitable skills-based training for the nurses, and appropriate specialist support, it is clear that the nurse-led model of care in the custodial setting offers the potential to substantially increase treatment uptake and reduce the burden of disease – both in the prisons and the community at large. Importantly, nurse led models also lend themselves to implementation in community settings. The new interferon-free treatments will further enhance this potential.

Professor Andrew Lloyd AM MBBS, MD, FRACP,
UNSW Australia and Justice Health & Forensic Mental Health Network

Ms Julie Babineau
Chief Executive, Justice Health & Forensic Mental Health Network

TARGETING PARTICULAR HEALTH SERVICES FOR TREATMENT EXPANSION

In addition to the establishment of treatment in correctional facilities, opioid treatment programs allow health teams to target populations with a high hepatitis C prevalence for assessment and treatment. A recent NSW study demonstrated the feasibility and effectiveness of such an approach.[47-49]

The role of publicly funded sexual health and HIV clinics in hepatitis C management and treatment will be explored, given 13% of people living with HIV are co-infected with hepatitis C.[50]

Aboriginal Community Controlled Health Services are well placed to provide hepatitis C screening, education, referral, support, management and treatment, given their multidisciplinary approach and extensive experience in providing chronic care services.

GENERAL PRACTICE

Although general practitioner prescribing (in a shared care model) is possible in NSW, and has been found to be safe and effective,[51] its uptake has been modest. This may be due to competing clinical demands, patient choice, dissatisfaction with shared care protocols and the complexity of care not being adequately supported under the Medicare Benefits Schedule to justify the ongoing training and prescribing accreditation requirements for general practitioners. A recent pilot study conducted in NSW found that general practitioner initiation of hepatitis C treatment was an effective, safe treatment option for some patients. If implemented at scale, this approach has the potential to increase access to hepatitis C treatment. NSW Health will explore the feasibility of expanding general practitioner initiation.

It is likely that new treatments will lend themselves to primary care models of service delivery, so involvement of primary care in treatment remains important. Barriers to the uptake of prescribing should be identified and addressed. Alternative ways of supporting general practitioner involvement in prescribing should also be pursued, through the Medical Benefits Schedule, PBS, engagement with specialist units, telehealth and co-location of hepatitis nurses.

PEER SUPPORT PROGRAMS

The involvement of people who have experience with hepatitis C or injecting drugs ('peers') in health programs and services may assist in engaging individuals in liver assessment and treatment who would not otherwise seek it out. Peers may also engender trust between clients and health service providers and facilitate the reorientation of services towards priority populations.[52]

“Ensuring that the affected community is meaningfully engaged in the response to hepatitis C in NSW is critical. As a state-wide community controlled drug user organisation representing those most affected by hepatitis C, the NSW Users and AIDS Association will play an important role in implementing this Strategy. Our community mobilisation and peer-driven models are effective and ensure that people who inject drugs remain at the forefront of the response. NSW Users and AIDS Association remains committed to driving down infections by scaling up prevention efforts through our Needle and Syringe Program and PeerLink Projects. We will also continue to implement strategies seeking to improve access to treatment and care, promote patient self-management – including the Liver Mates projects – and reduce stigma and discrimination.”

Ms Nicky Bath
Chief Executive Officer, NSW Users and AIDS Association

ACTIONS

Models of Care

- Agency for Clinical Innovation to lead efforts in establishing the most efficient and effective hepatitis C models of care.

  Partners: Ministry of Health, Local Health Districts and non-government organisations.

- Ministry of Health to enhance hepatitis C data systems to improve monitoring of clinical service activity, drive performance in hepatitis C treatment and assist in service planning.

  Partners: Local Health Districts and the Agency for Clinical Innovation.

- Local Health Districts to support correctional facilities, drug and alcohol services, sexual health services, HIV clinics, general practices and Aboriginal Community Controlled Health Services to expand treatment availability through clinical redesign, ensuring the availability of specialised hepatitis C nurses, training opportunities and partnerships with specialist hepatitis centres, and the integration of peer-based approaches.

  Partners: non-government organisations, researchers and Ministry of Health.

- Non-government organisations to implement models of peer-based support and education to engage people living with hepatitis C in liver assessments and contemplating hepatitis C treatment.

  Partners: general practice organisations, Multicultural HIV and Hepatitis Service and affected communities.

- Ministry of Health to implement strategies that engage more general practitioners and nurses to be involved in prescribing anti-viral therapy.

  Partners: non-government organisations and Local Health Districts.

- Local Health Districts to expand nurse-led models of care in community settings.

  Partners: Ministry of Health, general practice organisations, Aboriginal and Community Controlled Health Services and non-government organisations.

New Treatments

- Ministry of Health to work with the Australian Government to support general practitioner and nurse participation in hepatitis C treatment and management through the PBS, Medicare Benefits Schedule and other mechanisms.

  Partners: general practitioner organisations and non-government organisations.

- Ministry of Health to work with the Australian Government to maximise the accessibility of hepatitis C treatments for patient and public health benefit.

  Partner: Researchers.

- Ministry of Health to develop public and primary care communication strategies regarding hepatitis C treatment developments and availability.

  Partners: Local Health Districts, Aboriginal Health and Medical Research Council, researchers, non-government organisations and general practice organisations.

"Improving client access to hepatitis C services is an important priority for communities in Western NSW Local Health District, where hepatitis C notification rates are high. Expanding and integrating the partnerships between Local Health Districts, Aboriginal Community Controlled Health Services, clinical specialists and GPs is enabling residents of remote, rural and regional communities, better access to hepatitis C prevention, treatment advice and clinical services including diagnosis, monitoring and treatment. Nurse-led hepatology clinics in Bathurst, Orange and Dubbo provide outreach to Bourke, Walgett, Coonamble, Lightning Ridge, Brewarrina, Wellington, Cowra, Mudgee, Parkes, Forbes and Canowindra."

Debra Goodacre
Hepatology Nurse, Western NSW Local Health District

RESEARCH

During the life of this *Strategy*, the NSW Ministry of Health will invest in research that can guide the response to hepatitis C in NSW and support the achievement of our goals and targets. Studies that can directly inform the implementation or evaluation of the actions included in this *Strategy* will be prioritised. The Kirby Institute for Infection and Immunity in Society and the Centre for Social Research in Health are key partners in the NSW response to hepatitis C, through their work in epidemiology, clinical research, and behavioural and social research. Broad areas requiring research attention in NSW over the life of this *Strategy* include: the epidemiology of hepatitis C; the burden of disease in people living with hepatitis C; the reach and effectiveness of the NSP and other preventive strategies; management and treatment of hepatitis C in primary health care settings; and stigma and discrimination.

MONITORING AND EVALUATION

Monitoring and evaluation is a vital component of this *Strategy*. We will develop and implement an evaluation framework with input from stakeholders, including our research partners at the Kirby Institute for Infection and Immunity in Society and the Centre for Social Research in Health.

The focus is both to measure progress in achieving the *Strategy* goals and targets and to provide data on a regular basis to inform implementation decisions and drive better outcomes. Where possible, performance indicators will be developed for Local Health Districts to help local service delivery decision making and assess performance, in addition to measures identified in Service Agreements.

Throughout the life of this *Strategy* opportunities to improve regular data and reporting will be explored and implemented where appropriate. Further, evaluation of key responses will be undertaken to demonstrate outcomes and build evidence for practice.

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