We intend to pursue these objectives on behalf of people living with, affected by and at risk of viral hepatitis in NSW. This includes developing and implementing campaigns on the seven policy areas listed, and finding ways for people living with or affected by hepatitis B and hepatitis C to contribute actively to these activities. The Matters include (not listed in order of priority):

- **Continued Equal Treatment Access to hepatitis C medicines:** While Direct Acting Antivirals for hepatitis C have been listed on the PBS without restriction, continued work will be required to ensure that new drugs are listed without delay, and that the medicines that are listed on the PBS are able to be accessed by the people who need them.

- **Expand models of care to support increased treatment:** With increased treatment demand for both hepatitis B and hepatitis C, more training, resources and funding will be required to ensure a greater range of health services deliver this treatment in the community, including via general practitioners, alcohol and other drug services, opioid substitution treatment services and Aboriginal Medical Services.

- **Reduce stigma and discrimination against people with viral hepatitis:** Discrimination against people living with hepatitis B and hepatitis C is a negative in and of itself, but it also has flow-on impacts in terms of reduced engagement with healthcare services. Hepatitis NSW will campaign to reduce hepatitis-related discrimination across a wide variety of circumstances.

- **Expand Needle & Syringe Programs to NSW prisons:** The single most-effective new program to prevent hepatitis C transmission would be the introduction of needle & syringe exchange in NSW prisons, ensuring they can access the same, evidence-based harm reduction service that is available to the general community. This will also be essential to prevent re-infections following successful treatment and cure.

- **Improve hepatitis service delivery to people in regional, rural and remote NSW:** Hepatitis C notification rates are highest across rural and regional NSW. Hepatitis B is also more prevalent amongst Aboriginal people living in Far West and Western Districts. All people living with viral hepatitis deserve access to vital hepatitis prevention, management and treatment services, irrespective of where they live.

- **Increase testing for viral hepatitis, especially for hepatitis B:** Despite recent improvement, nearly 2-in-5 people living with chronic hepatitis B are undiagnosed. Without increased testing, people with hepatitis B, including many people from culturally and linguistically diverse backgrounds and Aboriginal people, will be unable to benefit from care and monitoring, and treatment, that could save their lives.

- **Encourage regular monitoring and, where relevant, treatment for people with hepatitis B:** Of people living with hepatitis B, only 62% have been diagnosed, only 15.7% are in regular care and only 6.3% are receiving treatment (whereas the national strategy treatment target is 15%). Hepatitis NSW will campaign to increase monitoring and treatment rates for people living with hepatitis B across NSW.
Hepatitis NSW, and especially our community mobilisation volunteers, played a key role in the successful campaign for all Australians living with hepatitis C to have equal access to new treatments.

This campaign has ensured that treatment is not restricted on the basis of a person’s liver disease stage (such as whether they have cirrhosis or not), how long they have been living with hepatitis C, the means of transmission involved or any prior treatment history.

As a result, Australia is one of the first countries in the world to have secured Equal Treatment Access to new hepatitis C drugs – and that achievement is something we should all be proud of.

However, while the principle of Equal Treatment Access has been won, many practical challenges remain. These include:

- Ensuring people who are at greater risk of progressing to liver cancer, such as people who already have cirrhosis and people living with hepatitis B or HIV coinfection, are able to access treatment as quickly as possible.

KURT SAYS

“Everyone with viral hepatitis deserves equal access to treatment. Thankfully Australians can access hepatitis C treatment before they progress to significant liver damage, but there we need to keep working to ensure all people living with hepatitis C actually get their hands on a cure.”

Hepatitis NSW will continue to campaign for Equal Treatment Access to hepatitis C medicines. This includes calling for new drugs to be listed on the PBS without delay, as well as ensuring the medicines that are listed on the PBS are able to be accessed by the people who need them.
The listing of new hepatitis C treatments on the Pharmaceutical Benefits Scheme in March, and May, 2016 caused a large, but welcome, wave of people to come forward for treatment. It is anticipated that this initial surge will gradually subside over the subsequent 12 to 18 months.

However, with even more new Direct Acting Antivirals expected to become available during the life of Hepatitis Matters, it is likely treatment rates will remain higher than they were on February 29, 2016. Indeed, Hepatitis NSW, together with partner organisations across the sector, will be working hard to ensure large numbers of people continue to come forward for treatment so that we can achieve the elimination of hepatitis C as a public health concern as quickly as possible.

Similarly, it is likely that the number of people requiring monitoring and treatment for hepatitis B will continue to increase in coming years, as the population of people living with hepatitis B ages. The number of people monitored and treated will, hopefully, also increase as a result of improved diagnosis rates (see also Increase testing for viral hepatitis, especially for hepatitis B).

The NSW Hepatitis B Strategy 2014-2020 itself commits to a target to "increase the number of people living with hepatitis B receiving antiviral treatment (when clinically indicated) by 300%".

These anticipated increases in treatment numbers for both hepatitis B and C, alongside the rise of other liver-related illness such as fatty liver disease, mean it is unlikely liver clinics alone will meet all viral hepatitis treatment demand, but will instead concentrate on providing care for people with advanced liver disease and liver cancer.

Consequently, an increasing share of treatment for both hepatitis B and C will be provided in the community – through general practitioners and other settings, such as alcohol & other drug services, opioid substitution therapy services, Aboriginal Medical Services (AMSs) and sexual health services.

Hepatitis NSW considers that this development is, or at least should be, a positive. It will allow treatment to be provided at a larger number of services, reducing geographic barriers. Providing treatment to the community, in the community, will also ensure people can access treatment at services where they are already comfortable:

- People living with hepatitis C, including people who inject drugs, can experience stigma and discrimination in some healthcare settings, meaning delivering treatment where they are is particularly important, while
- People living with hepatitis B, and especially people born overseas and Aboriginal and Torres Strait Islander people, may prefer to access general practitioners from within their community and/or culturally specific health services (such as AMSs) rather than liver clinics.

The challenge will be to ensure that appropriate models of care are developed to support the expected increase in both the number of people seeking hepatitis B and C treatment outside liver clinics, and also the greater range of health services involved in delivering this treatment. These models of care will also need to be supported with training for all staff that are newly-involved in treatment delivery, as well as possible additional investment in relevant services.

Hepatitis NSW will campaign for expanded models of care to support increased numbers of people being treated for hepatitis B and hepatitis C in the community. This includes calling for training, resources and funding to be provided to the greater range of health services involved in delivering monitoring and treatment.

ALLY SAYS

"With so many people requiring treatment and care we need a variety of different settings in which people can access that care. If someone is already a patient at a clinic, it seems logical that their hepatitis treatment should be at that clinic too"
For too many people, the experience of living with viral hepatitis is negatively affected by the stigma and discrimination that they encounter.

In terms of hepatitis C, this stigma can arise both because of a lack of knowledge and/or awareness around hep C generally, as well as discrimination because of its association with injecting drug use, itself a highly stigmatised activity, as the most common means of transmission in Australia.

Unfortunately, the discrimination which affects people living with hepatitis C can also arise in healthcare settings – previous studies have found almost 1 in 3 people living with chronic hep C reported being discriminated against by a health professional, including nearly 13% by a doctor. Evidence to the NSW Inquiry into Hepatitis C-Related Discrimination suggests that this discrimination can occur in hospitals, general practices, dental surgeries and other locations.

Stigma and discrimination in healthcare settings can have a range of negative impacts, including leading to poorer self-esteem and mental health outcomes, as well as discouraging the person living with hep C from engaging with the healthcare system in the future.

The stigma and discrimination experienced by people living with hepatitis B can be felt differently to that for hepatitis C, although it shares at least one cause: a lack of knowledge and/or awareness around hepatitis B in the community.

Other factors can that contribute to hepatitis B stigma and discrimination include the fact it is classified as a sexually transmissible infection (although that is not the most common means of transmission for people living with hep B in Australia), as well as negative treatment that people living with hep B may have experienced in their country of origin (such as discrimination in employment, education and access to healthcare in China).

Additionally, people living with hepatitis B are sometimes treated differently by family members and friends who incorrectly believe that hep B can be easily transmitted in social settings or by sharing crockery and cutlery or food when eating together. With people born overseas, especially in the Asia-Pacific, disproportionately affected by hepatitis B, there can also be significant differences between cultures in terms of how, and indeed whether, hep B is discussed.

As with hep C, the stigma and discrimination surrounding hepatitis B can create a major barrier which prevents people from engaging with healthcare generally, leading to lower testing rates, lower monitoring and treatment rates, and therefore poorer health outcomes overall.

Stigma relating to both hepatitis B and C can also be compounded by discrimination on other grounds, including discrimination against Aboriginal people.

We need to overcome stigma and discrimination against people living with viral hepatitis across society, including in healthcare settings. This is essential to protect the rights of people living with hepatitis B and C, as well as ensuring that they engage with the healthcare system for their health needs.

Hepatitis NSW will campaign to reduce the stigma and discrimination experienced by people living with hepatitis B and hepatitis C. This includes improving knowledge and awareness around viral hepatitis to overcome ignorance, as well as working with healthcare professionals to ensure that healthcare in NSW is delivered in a non-discriminatory way.
Prior to entering prison, 75% of people who inject drugs reported using sterile injecting equipment each time they injected BUT

While in custody, 70% of people who inject drugs reported sharing injecting equipment.

Prison NSPs have also been comprehensively shown to be effective by overseas experience in countries such as Switzerland, Germany and Spain, where programs have been shown to:

- Reduce risk behaviour and the transmission of the hepatitis C virus and of HIV
- Not increase drug consumption, or injecting
- Not endanger staff or prisoner safety, and in fact, make these settings safer places to live and work.

The introduction of prison NSPs would also particularly benefit Aboriginal people living with hepatitis C, who are disproportionately affected by this virus and who also continue to be incarcerated at rates far above their non-indigenous counterparts (although completely closing the gap in outcomes in this area depends on removing these disproportionate rates of imprisonment).

Given all of the above, Hepatitis NSW believes that it is time for needle and syringe programs to be introduced into NSW prisons as an effective – and proven – method to prevent the transmission of hepatitis C, and other blood borne viruses (BBVs).

MARY SAYS
“The introduction of needle & syringe programs in prisons is the single-most effective new initiative to reduce viral hepatitis transmissions. It would help prevent a significant number of new hepatitis C and other BBV transmissions in NSW”.

Hepatitis NSW will campaign to introduce NSPs in NSW prisons as a matter of priority to help reduce hepatitis C and other BBV transmissions, as part of a comprehensive harm minimisation approach. We believe this would be the single-most effective intervention to prevent new hepatitis C infections, and to prevent re-infections following successful treatment and cure.
In order to effectively combat viral hepatitis across NSW, all people need access to relevant health services, irrespective of where they live. For hepatitis C, this means access to prevention programs – including education, and needle & syringe programs. It also means access to effective monitoring and treatment.

The expansion of eligibility to prescribe new hepatitis C medicines, to include general practitioners in consultation with specialists, means that treatments will become increasingly accessible across NSW. However, there will continue to remain higher barriers to necessary resources, such as Fibroscan machines, and people with cirrhosis or other complex needs may continue to require treatment by specialists – which often involves travelling long distances.

The scale of the challenge in providing these services is confirmed by data showing that the five LHDs with the highest rates of hepatitis C notification adjusted for population are all in non-metropolitan NSW: Far West, Northern NSW, Mid North Coast, Western NSW and Murrumbidgee LHDs (with Hunter New England 7th, after only Sydney).

In contrast, hepatitis B is higher among people born overseas, with the five LHDs with the highest notification rates for hep B all located in metropolitan Sydney. Nevertheless, the 6th highest notification rate is for Far West LHD and for it, and other LHDs across regional, rural and remote NSW, a key challenge is in ensuring that hepatitis B testing, management and treatment is available for Aboriginal people who are disproportionately affected by hep B.

This includes ensuring Aboriginal Medical Services are resourced to respond to this demand, as well as improving the knowledge of and training for nurses and general practitioners in these areas. As with hepatitis C, some people with hepatitis B in non-metropolitan NSW will also require regular access to specialist liver services in larger centres.

Hepatitis NSW will campaign to ensure that people living with hepatitis C and hepatitis B in regional, rural and remote NSW have access to vital hepatitis prevention, management and treatment services, including support to access specialist services where necessary.
Increase testing for viral hepatitis, especially for hepatitis B

- People born in the Asia-Pacific (who account for an estimated 38% of people living with hep B in Australia) and
- Aboriginal and Torres Strait Islander people (who account for up to 10% of people living with hep B in Australia).

The proportion of people living with hepatitis C who are undiagnosed is comparatively smaller – 18% of the approximately 227,306 Australians living with hep C. However, that nevertheless equates to more than 40,900 people unknowingly living with an illness that still caused an estimated 818 deaths in 2015 in Australia.

In the era of new, interferon-free treatments for hepatitis C, providing high cure rates with short durations and limited side-effects, these people are also missing out on the treatment revolution that is now available to others. Increased testing rates for hep C, including for people who currently inject drugs, who have injected drugs in the past and for Aboriginal and Torres Strait Islander people and for people born overseas in countries of high hepatitis C prevalence will help individuals achieve cure, and help Australia move towards the elimination of hepatitis C as a public health concern.

For both hepatitis B and C, as well as engaging in testing campaigns that target priority population groups, consideration will also need to be given to implementing rapid testing technology to increase diagnosis rates over the life of this document.

Hepatitis NSW will campaign to increase testing rates for viral hepatitis, especially for hepatitis B given almost 40% of people living with hep B in Australia are currently undiagnosed. This will include culturally appropriate testing projects for people born overseas and Aboriginal and Torres Strait Islander people, and consideration of other initiatives such as rapid testing technology.
Encourage regular monitoring and, where relevant, treatment for people with hepatitis B

These very low figures are especially concerning when, without monitoring and, where necessary, treatment, 15-25% of people living with hep B will potentially die as a result of advanced liver disease and liver cancer.

Meeting this challenge will involve nearly all parts of the health system, including the Government, Local Health Districts, Aboriginal Medical Services, general practitioners and nurses, culturally-specific medical associations, multicultural health services, migrant services and especially the affected communities and their representative organisations.

This includes being sensitive to and respectful of different cultural approaches to hepatitis B specifically, and health issues more generally, such as approaches to privacy, and disclosure or non-disclosure among family members and within communities.

Above all, meeting this challenge will involve meaningful partnership with communities that are disproportionately affected by hepatitis B, including people born overseas – especially in the Asia-Pacific – and Aboriginal and Torres Strait Islander people.

The NSW Hepatitis B Strategy 2014-2020 includes a goal “to improve the health outcomes of people living with hepatitis B in NSW”, as well as an ambitious target to “increase the number of people living with hepatitis B receiving antiviral treatment (when clinically indicated) by 300%”.

As discussed elsewhere, this target cannot be met without increasing testing for hep B (see Increase testing for viral hepatitis, especially for hepatitis B).

However, it also will not be met without significantly increasing the proportion of people diagnosed with hepatitis B who are engaged in regular monitoring and management.

The 2016 Kirby Institute Hepatitis B and C in Australia: Annual Surveillance Report Supplement indicates the scale of the challenge – while 62% of Australians living with hep B have been diagnosed, only 15.7% are in regular care (which is essential to help prevent liver cancer) and just 6.3% are receiving antiretroviral drugs (whereas it is estimated 15% of people living with chronic hepatitis B would benefit from such treatment).

WEI SAYS
“Many Australians who are born overseas have had hepatitis B since they were children. The longer a person lives with hep B the greater their chance of developing liver disease and liver cancer. But there is effective treatment available that can keep hep B under control and prevent liver damage”