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2 March 2015

RE: Feedback on ACT Discussion Paper for the Development of ACT's Response to the National HIV, Sexually Transmissible Infection and Blood Borne Virus Strategies 2015-2017

The Health Care Consumers' Association (HCCA) welcomes the opportunity to provide written feedback on *the ACT Discussion Paper for the Development of ACT's Response to the National HIV, Sexually Transmissible Infection and Blood Borne Virus Strategies 2015-2017*.

The Health Care Consumers' Association (HCCA) of the ACT was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

As a peak body, we work closely with individual and organisational members to ensure consumer voices are heard in the ACT Health system. This submission has been informed by the input of one of our member organisations Hepatitis ACT. We strongly support Hepatitis ACT position on the, *Development of ACT's Response to the National HIV, Sexually Transmissible Infection and Blood Borne Virus Strategies 2015-2017 (ACT BBV and STI Response)* and their submission to your team regarding the ACT BBV and STI Response.

Background

- Viral hepatitis chronically affects 7,600 Canberrans. This number is increasing, with 295 people diagnosed with either hepatitis B or C in 2013.
- Untreated viral hepatitis is the leading cause of primary liver cancer in Australia. Liver cancer is now the fastest increasing cause of cancer death in Australia.
- Liver cancer has one of the lowest survival rates. Latest AIHW research reveals that the number of new cases of liver cancer each year (1,446) is matched by the number of lives lost to the disease (1,419) annually. This means that for every Australian diagnosed with liver cancer, another Australian loses their life. Liver cancer had a death-to-incidence ratio of 0.98 (almost one death for every new case), compared with much lower ratios for breast cancer (0.2), prostate cancer (0.16), melanoma (0.13), bowel cancer (0.26), and even lung cancer (0.77).
- Without a major increase in hepatitis treatment, experts predict a 245 per cent increase in liver cancer from hepatitis C alone by 2030. Currently, only 1 per cent of the 233,000 Australians living with hepatitis C are treated each year. Liver cancer death rates are projected to be even higher by 2030 when hepatitis B is taken into account. More than 225,000 Australians are living with hepatitis B, but only half are diagnosed and only five per cent are treated.
- The adoption and implementation of the national strategies' key guiding principles is a positive development.
- The proposed priority populations are good but do not include 'people living with hepatitis B'.
- All Australian Health Ministers endorsed the targets included in the national strategies, and therefore those targets should be reflected in the ACT Response priority actions.

Suggested ACT Priority Actions

Fourth National Hepatitis C Strategy 2014-2017

- Advocate for and support timely and broad-based access to newly developed and proven treatments for HCV through the Pharmaceutical Benefits Scheme
- Increase by 50% each year the number of people undergoing treatment for hepatitis C, including through shared care models
- Reduce the incidence of new hepatitis C infections by 50% by increasing access to education and prevention strategies, including expanding access to sterile injecting equipment in community and correctional settings
- Improve collection, analysis, reporting, and publication of viral hepatitis treatment and surveillance data in the ACT
- Increase the number of people living with viral hepatitis accessing high quality and regular liver check-ups

Second National Hepatitis B Strategy 2014-2017

- Increase vaccination amongst eligible and at-risk priority populations, including for those working in high-risk occupations
- Ensure access to appropriate prevention, testing, treatment and support services for people from culturally and linguistically diverse backgrounds living with or at risk of hepatitis B
- Increase to 15% the proportion of people living with chronic hepatitis B undergoing antiviral treatment for hepatitis B
- Support targeted messages to people living with or at risk of hepatitis B on the importance of prevention, testing, monitoring and treatment

What information do we need to mointor progress? Do we currently have access to this information? If not, what needs to change?

HCCA is aware that unfortunately there is no hepatitis treatment data publically made available by ACT Health. This means that ACT community has no way of knowing basic, but important information such as numbers of people treated or not treated, success rates of treatments, waiting list periods, numbers of people monitored. The absence of data is problematic when it comes to designing this

ACT BBV and STI Response. We strongly urge that this data be made available publically and that it is used to shape the ACT BBV and STI Response.

We would welcome any opportunity to provide further specific comments on the ACT BBV and STI Response and would be happy to meet with you to discuss this further.

Yours sincerely,

Darlene Cox
Executive Director

2 March 2015