

Submission for consideration: Development of Victorian cancer plan 2020-2024

Hepatitis Victoria proposes that priority focus is given to liver cancer in the Victorian Cancer Plan 2020–2024, in accordance with its increasing prevalence and mortality and morbidity rates.

This priority focus on liver cancer must be accompanied by implementation drivers, specifically:

- Targets that focus on the reduction of liver cancer and its earlier detection
- Measures of prevalence of liver cancer, along with continued measures of contributing factors such as viral hepatitis, in an outcomes framework
- Clear monitoring at identified intervals within the outcomes framework and associated reporting
- Identified accountabilities for all charged with achieving specific targets
- Commitment to resourcing the work required (health promotion, education, stigma reduction, etc) to undertake the identified priority actions to achieve the established targets.

Hepatitis Victoria submits that actual consumer experience is critical in shaping the actions needed to transform the well-being of people with liver disease and liver cancer, particularly given the associated stigma and lack of awareness.

LiverWELL[™] trading under the name of Hepatitis Victoria thanks the Department of Health & Human Services for this opportunity to participate in the consultation process that will inform the state-wide cancer plan for the next four years. Please consider the following submission in the development of the Victorian cancer plan 2020-2024

Introduction

Liver cancer has the fastest growing mortality rate of all cancers in Australia. With a five-year survival rate of 18%¹, there were 1,864 deaths caused by liver cancer in Australia in 2016. This is significantly higher than the number of deaths caused by the road toll (1,293 in 2016).

The biggest known risk factor for primary liver cancer is viral hepatitis, with an estimated 71% of cases of liver cancer globally being a consequence of either hepatitis B and or hepatitis C². Although mortality rates are decreasing for most cancer types, liver cancer is one notable exception. Despite recent advances in cures for hepatitis C and vaccination programs for hepatitis B, the mortality rate for liver cancer continues to increase.

Australia has had some success with the uptake of direct acting antiviral medicines (DAAs) which cure hepatitis C and with immunisation rates for hepatitis B. This has prompted the Victorian government to release state strategies for both hepatitis B and C which align with the World Health Organisation's 2030 elimination target. Nonetheless, Kirby Institute data³ shows that the rate of uptake of the DAAs is declining and if this trend continues, the elimination of viral hepatitis as a public health threat will be jeopardised.

¹ <https://www.cancer.org.au/about-cancer/types-of-cancer/liver-cancer.html>

² https://wiki.cancer.org.au/policy/Liver_cancer/Causes#Progression_to_hepatocellular_carcinoma

³ https://kirby.unsw.edu.au/sites/default/files/kirby/report/Monitoring-hep-C-treatment-uptake-in-Australia_Iss9-JUL18.pdf

Who we are: LiverWELL™

LiverWELL™ is a registered charity, trading under the name Hepatitis Victoria. We are the peak not for profit, community organisation committed to reducing the impact of viral hepatitis and liver disease. We provide information, support, referral, education and advocacy for people living with viral hepatitis and liver disease and training for those who work with them. We strive for maximum impact, building on evidence, being innovative and driving change to achieve better liver health for all.

LiverWELL™ is uniquely placed to implement the outcomes identified in the Victorian Cancer Plan 2020-2024 as we have more than 25 years' experience of engaging and educating the community and conducting evidence-based approaches to programs through our ongoing partnerships with clinical, research and government agencies.

Proposals for consideration

Implementation plans for Victoria Hepatitis Strategies

The Victorian government has been rightly commended for the level of consultation and consideration undertaken in the development of the Victorian Cancer Plan 2016-2020, as well as the development of the Victorian hepatitis B strategy 2016-2020 and the Victorian hepatitis C strategy 2016-2020. These documents clearly outline many of the priority areas required to effectively reduce mortality resulting from liver cancer.

Unfortunately, the lack of implementation drivers such as sustained awareness campaigns targeting high prevalence communities, has weakened the potential for achievement of the positive outcomes included in these strategies and has reduced the positive difference that could have been made to the health of Victorians.

As outlined in these existing plans and strategies, the people at greatest risk of developing liver cancer are from marginalised communities, such as prisoners, Aboriginal and Torres Strait Islanders, people who inject drugs and migrants and refugees from high prevalence regions.

- **Hepatitis Victoria suggests that in addition to the consultation currently being undertaken for the 2020–2024 cancer plan, the next iteration of the State strategies for hepatitis B and hepatitis C should be developed with a similar level of commitment; these documents must be accompanied by implementation plans and commensurate funding to ensure that outcomes are verified and the commitment to elimination of viral hepatitis as a public health threat by 2030 is maintained.**
- **Hepatitis Victoria strongly recommends that the Victorian cancer plan 2020-2024 be accompanied by a robust implementation strategy with goals and timelines for its implementation.**

Stigma and discrimination

The Victorian cancer plan 2016-2020 states that stigma and discrimination are major barriers to health and wellbeing. This has also been declared as a priority in the state strategies for viral hepatitis. Currently there is no evidence that the levels of stigma and discrimination associated with viral hepatitis and liver cancer are diminishing. Hepatitis Victoria is well placed to tackle stigma and discrimination, and with the right investment, much could be achieved in working with community and health workforces to address attitudes towards stigma and discrimination regarding viral hepatitis, liver disease and liver cancer.

Liver Cancer: prevention and screening

As outlined in the current cancer plan, prevention is key to reducing the increasing rates of hepatitis-related liver cancers.

Screening and early detection of liver cancer results in better outcomes. Every Victorian should understand their risk of cancer and be supported to manage their own health⁴. Screening should be a priority for people at

⁴ Victorian cancer plan 2016–2020, ISBN 978-0-7311-6990-0

high risk of developing liver cancer. Similarly, screening of people living with cirrhosis (often a precursor to liver cancer) should also be a priority consideration.

Equitable access: barriers to prevention and treatment

Access to treatment should be equitable for all Victorians. During the consultation period for the development of the revised cancer plan, there has been some discussion of the importance of equitable access to health care, screening and treatment. This discussion has centred around urban compared to rural access, and difficulties for people from culturally and linguistically diverse communities. However, it fails to consider equitable access for people with mental health conditions, people with addictions, homeless access and people in custody. For example, mental health hospital in-patients are not covered by the Pharmaceutical Benefits Scheme and are therefore do not have access to direct acting anti-virals (DAAs).

- **Hepatitis Victoria suggests that an effective cancer plan must be inclusive of society's most marginalised communities, as these groups have some of the poorest health outcomes. Although this may be the most challenging outcome to achieve, with the need to develop policies which enable social reform such as safe injecting facilities for prisons, a progressive plan with strategies and goals for tackling such difficult issues should be developed.**

Causes of liver cancer: screening and surveillance saves lives

Viral hepatitis and multiple other factors such as non-alcoholic fatty liver disease (NAFLD), obesity and diabetes amongst others contribute to the burden of liver disease and liver cancer. Hepatitis Victoria supports Victorian community members who make enquiries and seek information about all forms of liver disease. These broader enquiries about liver disease are increasing as a percentage of the total number of calls received by the Hepatitis Victoria InfoLine, support and referral service. This service plays an important role in connecting at risk individuals to screening and care. It would play an even more important role if resources are made available to extend its capabilities and remit.

Regardless of the potential causes of liver cancer, it has been acknowledged that at risk patients who are on surveillance programs are almost twice as likely to be cured, as opposed to those who are diagnosed outside a surveillance program where liver cancer is twice as likely to be advanced and incurable⁵. This clearly demonstrates that investment in surveillance of at-risk groups saves lives.

- **Hepatitis Victoria recommends that investment in surveillance of at-risk groups should incorporate providing support to clinicians through effective screening programs and the development of effective community education programs. By committing to effective health promotion campaigns for at risk communities and the general public, a collaborative approach to saving lives can be developed.**

Role of primary care and integrated hepatitis nurses

The data clearly shows that a large proportion of people living with hepatitis B are lost in the cascade of care between being diagnosed and receiving care⁶. Although this is a complex issue, primary care practitioners are best placed to address it. Referrals to specialist care may be problematic in some jurisdictions, as waiting lists are extensive. Therefore, Hepatitis Victoria recommends that training be provided for general practitioners and support provided to them by the Department of Health and Human Services on the recommended actions to be taken for follow up upon receipt of a hepatitis B notification. Practical support for primary care is currently provided by the Victorian network of integrated hepatitis C nurses. Feedback from the people affected by viral hepatitis and liver disease endorses that this network provides valued support.

- **Hepatitis Victoria proposes the expansion of the Victorian network of integrated hepatitis C nurses would have a positive and measurable impact on health outcomes.**

⁵ Professor Alex Thompson-Gastroenterologist, St Vincent's Hospital, Personal correspondence 2019.

⁶ Viral Hepatitis Mapping Project: National Report 2017 Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM). ISBN: 978-1-921850-30-1.

Conclusion

As the Victorian cancer plan 2020-2024 is developed, there is an opportunity to reflect upon progress towards the goals laid out in the first and previous iteration of the cancer plan. To avoid any perception that development of a cancer plan is an outcome and a substitute for action and accountability, the rigorous tracking of goals, milestones and achievements and assignment of responsibilities must be explicit. The focus on outcomes must be applied across strategies and policies that support the objectives, and nowhere is this as important as for the state liver disease and viral hepatitis strategies.

Hepatitis Victoria reiterates the following key considerations for the development of the Victorian cancer plan 2020-2024:

- **Liver cancer be given a priority focus with its increasing prevalence and mortality and morbidity rates**
- **The focus on liver cancer must be accompanied by implementation drivers with targets for the reduction of liver cancer rates and earlier detection of liver cancer, as well as measures of prevalence of liver cancer and the contributing factors such as viral hepatitis and other liver diseases**
- **For these implementation drivers to be effective, an outcomes framework with clear monitoring and associated reporting of the earlier detection and incidence rate of liver cancer must be included**
- **To effectively reduce the impact of diseases like cancer, development and implementation of strategic plans such as this must take an approach that includes clinicians and researchers.**
- **As importantly, they must take prevention matters into consideration by engaging with the affected communities and drawing on the reflections of those with lived experience**
- **Awareness raising campaigns and education must be available and tailored for stakeholders, whether they be specialists, allied health practitioners or consumers.**

Hepatitis Victoria emphasises that there must be a commitment within the Victorian cancer plan 2020-2024 to adequately resource the work required (health promotion, education, stigma reduction, etc) to undertake the identified priority actions and achieve the established targets. Along with ensuring accountabilities are identified for all charged with achieving the plan's outcome targets.

Hepatitis Victoria encourages the Victorian Government to utilise the community and not for profit sector's vast experience with health promotion, health prevention, screening, testing and treatment promotion to reach those who need it most when implementing the Victorian cancer plan 2020-2024.