

# Roadmap to Liver Cancer Control in Australia

Developed by Cancer Council Australia & The Daffodil Centre, in collaboration with the Expert Advisory Group for the Roadmap to Liver Cancer Control.

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Cancer Council Australia acknowledges the traditional custodians of the lands on which we live and work. We pay respect to Aboriginal and Torres Strait Islander Elders past, present and emerging.

## **Overview**

The Roadmap to Liver Cancer Control (the Roadmap) has been developed to reduce the disease burden, improve outcomes and improve survival rates for all Australians affected by liver cancer. The Roadmap identifies key priorities over the next 2, 5 and 10 years, in line with the timeframes outlined by the Australian Cancer Plan. The Roadmap paves the most efficient and effective way to achieve the priority actions and sets a shared agenda to drive improvements in liver cancer care, experience and outcomes. The key priority actions were developed under the guidance of an Expert Advisory Group (Appendix A) and in consultations with key stakeholders.

The scope of this Roadmap focuses on the early part of the liver cancer continuum, from prevention to early detection and treatment access.

Providing culturally sensitive and safe health care is central to enhancing liver cancer outcomes by improving health literacy, awareness, understanding and utilisation of liver cancer control activities. This is critical for high-risk populations, as cultural determinants of health alongside the ongoing effects of colonisation, systemic racism, stigma and social marginalisation have impacted health care provision. Culturally sensitive and safe health services can be provided through understanding, consideration and respectful accommodation of an individual's cultural, linguistic, religious, sexual and racial/ethnic characteristics to ensure that all are welcome, safe and protected. These are important issues and considerations for the delivery of health care as it relates to liver disease and liver cancer.

In developing the Roadmap, effort has been made to ensure the focus for future actions remains on priority highrisk populations in terms of liver cancer. In the Australian context, high-risk populations include Aboriginal and Torres Strait Islander people, culturally and linguistically diverse populations and those living in remote areas. This is consistent with the Australian Government's focus on reducing health inequities in Australia through support of the National Agreement on Closing the Gap, the Australian Cancer Plan and Aboriginal and Torres Strait Islander Cancer Plan, and strategies and frameworks already in place.

# **Priority Actions**

### CAUSES OF LIVER CANCER

**1** Prioritise the robust linkage of collected data to inform liver disease and liver cancer patient characteristics and outcomes (*2yrs*)

#### PREVENTION Work with key stakeholders to ensure liver cancer issues are integrated into forthcoming and 2 existing cancer related frameworks and strategies (2yrs) Implement the National Hepatitis B & C Strategies to improve early detection and treatment 3 adherence as well as reduce stigma and discrimination in acknowledgment of the impact on liver cancer outcomes (2yrs) Support for funding of actions within the National Preventive Health Strategy for non-4 communicable diseases, especially tobacco control (2yrs) Raise awareness of risk factors among the community and primary health care workers to 5 promote prevention activities of liver disease and liver cancer (2yrs) Fund targeted education campaigns to increase awareness of liver cancer in Aboriginal and Torres 6 Strait Islander communities and culturally and linguistically diverse groups (2yrs) Raise awareness of both advanced liver disease/cirrhosis and HCC and the strong link between the 7 two in primary care by including earlier identification of HBV, HCV and advanced liver disease as well as HCC surveillance and management in primary care guidelines (2yrs) Build capacity and infrastructure in primary care to integrate liver-related health services (liver risk 8 assessments, referral pathways etc) (5yrs)

**9** Prioritise research activities identifying advanced liver disease/cirrhosis to build the evidence base, especially around the implementation of risk assessment tools to facilitate the identification of high-risk patients (*2yrs*)

## TARGETED SCREENING FOR ADVANCED LIVER DISEASE AND HCC SURVEILLANCE

- **10** Facilitate the availability and funding of tests and equipment to screen for advanced liver disease to communities of highest need (*2yrs*)
- **11** Use emerging evidence in advanced liver disease/cirrhosis identification to determine if it can be feasibly, effectively and equitably implemented in Australia (*5yrs*)
- **12** Continued investment in the dissemination of the 2023 HCC surveillance guidelines awareness and education activities (*2yrs*)
- **13** Develop a framework, including funding structure, that ensures the 2023 HCC surveillance guidelines remain current, based on new evidence and continue to meet NHMRC requirements (2yrs)
- **14** Optimise existing HCC surveillance management system and patient recall and abnormal-results notification systems embedded in primary care (*2yrs*)
- **15** Investigate a viable process model to provide guideline recommended HCC surveillance for highrisk patients in Australia (including cost-effectiveness) (2yrs)

## **Priority Actions**

TARGETED SCREENING FOR ADVANCED LIVER DISEASE AND HCC SURVEILLANCE

- **16** Investigate processes and new models of care to support reducing HCC surveillance burden on health service providers, assist with patient recall and improve data collection for HCC surveillance (2yrs)
- **17** Establish and implement a national HCC surveillance management system or the patient recall system to support HCC surveillance implementation (*5yrs*)
- **18** Optimise the access and provision of culturally appropriate navigation support for high-risk patients undergoing HCC surveillance and HCC patients (*5yrs*)
- **19** Undertake systems mapping of the healthcare system to inform the development of a pilot national HCC surveillance program (*5yrs*)
- **20** Establish and systematically implement a national HCC surveillance program with particular attention given to a coordinated data management system, allied health provision and equitable access to care (*10yrs*)
- 21 Prioritise research to ensure the equity of access and availability of HCC surveillance services (2yrs)

## DIAGNOSIS, STAGING AND TREATMENT PLANNING

**22** Improve post-treatment surveillance for liver cancer patients and improve connections in optimal care pathways, especially in transient communities and culturally and linguistically diverse communities (*2yrs*)

## SUPPORTIVE AND END-OF-LIFE CARE

- **23** Provide education to health providers in providing HCC related care in a culturally safe and sensitive way (2yrs)
- 24 Develop culturally sensitive and safe services to provide support post-treatment to liver cancer patients and their carers (2yrs)
- 25 Support and fund resources to meet liver cancer patient needs along the continuum of care (5yr)
- 26 Explore and address equity issues in access and availability of palliative care to HCC patients (2yrs)

## Liver cancer in Australia

Liver cancer, of which hepatocellular carcinoma (HCC) accounts for the greatest burden, has increased rapidly in incidence and mortality in Australia over recent decades and is projected to increase further by 2044 (1,2) [see Figure 1]. The Northern Territory recorded the highest liver cancer incidence and mortality rates for liver cancer in 2015, both 13 per 100,000 people (3). Liver cancer mortality rates in Australia continue to grow faster than any other cancer in Australia (1). Liver cancer incidence rates are higher amongst males (3 times that in females) (1).



Figure 1: Liver cancer statistics in Australia. Sources: AIHW Cancer data in Australia 2022; Luo Q et al Lancet Public Health. 2022 Jun 1;7(6):e537-48.

## **Causes of liver cancer**

A significant proportion of liver cancers are preventable through primary prevention strategies to reduce or eliminate transmission of the hepatitis B virus (HBV) and the hepatitis C virus (HCV), and through early detection and appropriate management and treatment of infected individuals. Key liver cancer risk factors include chronic infection with HBV or HCV and behavioural and metabolic risk factors also associated with other chronic diseases (including excessive alcohol use, tobacco consumption and excess adiposity) (4). The Global Burden of Disease Study estimated that from 1990-2015, alcohol and HCV were the risk factors to which the majority of liver cancer cases in Australia were attributable (approximately 39% each) (5).

However, the understanding of liver cancer in Australia is limited due to known issues with the timeliness of data availability and that currently available data do not provide a picture of the burden by subtypes or by individual socio-demographic factors. Addressing these data issues to better facilitate our understanding of the liver cancer burden, staging and treatment uptake is critical to improve outcomes into the future. This will improve our understanding of outcomes by patient characteristics (e.g., country of birth, ethnicity, language spoken at home, Aboriginal and Torres Strait Islander status, socioeconomic status), aetiology, staging, treatment and patient reported outcomes and facilitate health care planning not only for liver cancer control, but benefitting other cancer outcomes as well. While there is significant work underway within cancer registries, organisations, and research teams to improve our understanding of liver cancer with enhanced data, it is critical that the data we currently have is best utilised to improve outcomes. Developing and executing a robust plan to support the linkage of existing data and employing this linked data to support system improvement, while continuing to work on data enhancements, is essential to improve liver cancer outcomes in Australia.

Prioritise the robust linkage of collected data to inform liver disease and liver cancer patient characteristics and outcomes (2yr)

## Prevention

The commonalities between liver cancer risk factors and modifiable risk factors for other chronic diseases such as alcohol consumption, tobacco use and sugar consumption, support clear calls for action in linking forthcoming and existing frameworks to leverage the impact on liver cancer control.

It will be essential to integrate the priority actions for liver cancer with the:

- » The Australian Cancer Plan, and
- » The Aboriginal and Torres Strait Islander Cancer Plan.

The Roadmap closely aligns with the Australian Cancer Plan 5-year goal of strengthening the policy and regulatory environment to address known modifiable lifestyle factors and social, cultural, and commercial determinants of health; and the 2-year goal to deliver cancer prevention and health promotion activities, including healthy lifestyles, immunisation, and population screening participation, co-designed and tailored to a range of settings.



Work with key stakeholders to ensure liver cancer issues are integrated into forthcoming and existing cancer related frameworks and strategies (2yr)

Policy and strategies aimed at managing chronic infection with HBV and HCV have significant potential to reduce Australia's current and future liver cancer burden. Australia has a number of national strategies for hepatitis control, and was the first country in the world to have a national strategic response to hepatitis C. Major frameworks currently include (noting several are under review):

- Fifth National Hepatitis C Strategy 2018-2022;
- Third National Hepatitis B Strategy 2018–2022;
- National Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy 2018-2022;
- National Hepatitis C Testing Policy; and
- National Hepatitis B Testing Policy.

The National Hepatitis B and C Strategies and Policies highlight important issues that, if left unaddressed, will contribute to increasing the liver cancer burden and, thus, their full implementation is supported as part of this Roadmap.

PRIORITY

3

Implement the National Hepatitis B & C Strategies to improve early detection and treatment adherence as well as reduce stigma and discrimination in acknowledgment of the impact on liver cancer outcomes (2yr)

The successful treatment of HBV and HCV with high curative rates has seen a change in the prevalence of the causes of liver cirrhosis and cancer which are shifting to metabolic-associated fatty liver disease and alcohol related liver disease (6-8). Smoking, and the use of tobacco, also continues to be a significant attributable factor to liver cancer (21% of liver cancer cases were attributed to tobacco consumption in 2010 (9)). As a result, policies and interventions that support healthy lifestyles, a comprehensive nationally coordinated approach to tobacco control and strategies to reduce sugar consumption (such as a sugar levy), may contribute to reducing risk. The World Health Organisation (WHO) best buys interventions, which include alcohol control strategies to prevent and reduce harm, are recommended intervention for implementation. Australia's approach has been outlined in the National Preventive Health Strategy 2021-2030 with specific targets set to achieve a national daily smoking prevalence of less than 10% by 2025, 5% for adults by 2030; and to reduce the daily smoking rate among Aboriginal and Torres Strait Islander people to 27% or less by 2030. Targets have also been set to see at least a 10% reduction in harmful alcohol consumption by Australians by 2025 and a 15% reduction by 2030 for those over 14 years of age. The Roadmap supports implementation, funding and evaluation of the National Preventive Health Strategy's actions, especially as they relate to non-communicable diseases. The National Alcohol Strategy 2019-2028 also acknowledges the contribution of alcohol to the development of some cancers and chronic liver disease, stating that action is needed to further educate Australians about lower risk drinking, including in relation to health impacts of drinking (e.g., links with cancer and liver disease) (10).

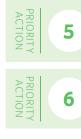
## Prevention



Support for funding of actions within the National Preventive Health Strategy for noncommunicable diseases, especially tobacco and alcohol consumption (2yr)

The existence of specialised interventions, including surgical or therapeutic options for weight loss have been identified as some of the mechanisms to improve liver cancer outcomes. However, their equitable availability and accessibility are limited due to lack of subsidies and high out of pocket costs. The continued use of these interventions may further exacerbate inequalities in liver cancer outcomes for Australians.

Evidence highlights the need to engage with the community, especially priority populations, primary health care professionals, the community-controlled sector or local clinics on-Country, and policy makers to improve liver cancer related awareness and understanding along with their resourcing and utilisation of liver cancer control activities. For this Roadmap, the focus remains on Australian priority high-risk populations, which include Aboriginal and Torres Strait Islander people, culturally and linguistically diverse populations, and those living in remote areas, with support for strategic communication campaigns and education activities to improve health literacy and understanding. It will be essential to coordinate with other education campaigns and ensure that genuine co-design and community based approach with each language group occurs from the outset. Beyond community awareness raising, effort should be focused at supporting primary care health professionals to work with individuals around increasing testing and diagnosis.



Raise awareness of risk factors among the community and primary health care professionals to promote prevention activities of liver disease and liver cancer (2yr)

Fund targeted education campaigns to increase awareness of liver cancer in Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse groups (2yr)

## Prevention

Increased education efforts are needed for primary care professionals to improve clinical understanding, ideally building liver risk assessment and prevention strategies into general health checks. It is critical to invest in improved capacity of primary care professionals and systems to address liver health, liver related risk factors and liver diseases.



Raise awareness of both advanced liver disease/cirrhosis and HCC and the strong link between the two in primary care by including earlier identification of HBV, HCV and advanced liver disease as well as HCC surveillance and management in primary care guidelines (2yr)

Primary care is integral to targeted screening of advanced liver disease. Primary health care professionals and practices are well placed to provide comprehensive liver risk assessment and facilitate access to appropriate care (based on the existing guidelines). This includes the community-controlled health sector and local clinics on-Country, who provide primary care directly to target populations. However, improved education and infrastructure to support this being actioned is critical. Additional clinically focused education is needed to ensure that primary health care professionals, especially general practitioners, are aware of the potential development of liver disease, cirrhosis and liver cancer, particularly for people with chronic hepatitis infection. Infrastructure changes could begin with practice software-based prompts to identify potential high-risk patients, and clinical audits to facilitate the identification of patients, noting further evidence is needed in patient identification and the implementation of risk assessment tools in practice. These additional skills and tasks would need further training and potential reimbursement. More can be done in the Australian context to build knowledge through research activities. Any research activities that are undertaken should prioritise the involvement of Aboriginal and Torres Strait Islander researchers and communities, following data sovereignty principles.



**Build capacity and infrastructure in primary care to integrate liver-related health services** (liver risk assessments, referral pathways etc) (5yr)

PRIORITY ACTION Prioritise research activities identifying advanced liver disease/cirrhosis to build the evidence base, especially around the implementation of risk assessment tools to facilitate the identification of high-risk patients (2yr)

## Targeted screening for advanced liver disease and HCC surveillance

Overall, there is promising evidence to support targeted screening of advanced liver disease and HCC surveillance in line with the guidelines (11). Consideration has been given to screening for advanced liver disease and identified evidence to support screening programs in primary care settings that increased the diagnosis rate of advanced liver disease, a precursor of HCC, despite the lack of randomised results (12). Further exploration of targeted screening requires availability and access to suitable tests and equipment to identify advanced liver disease (e.g., APRI, Fib4). Currently there is a lack of equitable availability across Australia especially in communities of highest need, which should be addressed. As these tests become more integrated into practice, the capacity of primary health care professionals needs to be supported through funding and infrastructure.

PRIORITY ACTION ACTION

Facilitate the availability and funding of tests and equipment to screen for advanced liver disease to communities of highest need (2yr)

Use emerging evidence in advanced liver disease/cirrhosis identification to determine if it can be feasibly, effectively and equitably implemented in Australia (5yr)

A key component of this Roadmap has been the development of the *Clinical practice guidelines for hepatocellular carcinoma surveillance for people at high risk in Australia 2023* (11). The implementation of the HCC surveillance guideline recommendations in practice requires continued investment to support their dissemination through awareness and education activities. This is especially important with clinicians across the health care system including primary care, drug and alcohol services, and Aboriginal and Torres Strait Islander community-controlled health services and local clinics on-Country. Prioritised co-design processes and research to ensure equity of access and availability and community acceptability of HCC surveillance services may be required to identify the best approach to service delivery by regions and/or populations in a culturally sensitive and safe way. The national implementation of an HCC surveillance program is of utmost importance however there is a need to pre-empt this with a healthcare system mapping exercise and a pilot or demonstration study to ensure its long-term success is supported by a coordinated data management system, allied health provision and equitable access. It will be imperative that this system mapping considers the range of information management systems used across various health services, including the community-controlled sector and local clinics on-Country, and variations across states and territories. It is also important to map services are available for Aboriginal and Torres Strait Islander people.

PRIORITY ACTION	12	Continued investment in the dissemination of the 2023 HCC surveillance guidelines awareness and education activities (2yr)
PRIORITY ACTION	13	Develop a framework, including funding structure, that ensures the 2023 HCC surveillance guidelines remain current, based on new evidence and continue to meet NHMRC requirements (2yr)
PRIORITY ACTION	14	<b>Optimise existing HCC surveillance management system and patient recall and abnormal- results notification systems embedded in primary care</b> (2yr)

# Targeted screening for advanced liver disease and HCC surveillance

<b>15</b> Investigate a viable process model to provide guideline recommended HCC survives high-risk patients in Australia (including cost-effectiveness) (2yr)	/eillance for
<b>16</b> Investigate processes and new models of care to support reducing HCC surveill on health service providers, assist with patient recall and improve data collection surveillance (2yr)	
<b>TO Establish and implement a national HCC surveillance management system or p</b> <b>system to support HCC surveillance implementation</b> (5yr)	atient recall
<b>18</b> Optimise the access and provision of culturally appropriate navigation support risk patients undergoing HCC surveillance and HCC patients (5yr)	t for high-
<b>19</b> Undertake systems mapping of the healthcare system to inform the development of the healthcare system t	ent of a pilot
<b>20</b> Establish and systematically implement a national HCC surveillance program was particular attention given to a coordinated data management system, allied h provision and equitable access to care (10yr)	
PRIORITY Prioritise research to ensure the equity of access and availability of HCC survei services (2yr)	llance

## Diagnosis, staging and treatment planning

Diagnosis and treatment related issues regarding highly mobile patient populations and resulting variable access to health services and treatment issues as they relate to liver cancer control, is important for consideration. The provision of primary care services to these individuals as well as information about liver cancer, treatment options and supportive care are essential to support successful detection, surveillance and treatment.

Variations of care are an active priority area for people with cancer, as noted in the Australian Cancer Plan. Liver cancer care could be improved through systematic reporting of care provided, treatment choices and patient reported outcomes. This information would help inform future health care decisions, policy and planning to address variations in care and improve equitable access to care. There is a need to facilitate funding for all testing required to provide appropriate liver cancer care. There are noted challenges in ensuring that people with liver cancer are enrolled in care after their diagnosis due to limitations in communicating the importance of care uptake (especially in culturally and linguistically diverse communities) and accessibility of care (especially in transient communities). Once available, the provision of coordinated care for people with liver cancer is recommended to be provided through multidisciplinary teams (MDTs), based on evidence-based guidelines.



Improve post-treatment surveillance for liver cancer patients and improve connections in optimal care pathways, especially in transient communities and culturally and linguistically diverse communities (2yr)

## Supportive and end-of-life care

Given growing rates of liver cancer, consideration for supportive and end-of-life care is receiving more attention, with a need to enhance the availability of suitable services and improve the understanding of patient needs. It can be challenging for individuals with liver cancer and their families and carers to navigate through the health care system, especially as liver cancer is typically treated by professionals and teams from different medical streams, and so there is an important need to support patients and carers through this process in a culturally safe and appropriate way. This can be facilitated through supporting and funding culturally appropriate supportive care services in the health care sector for people with liver cancer. Culturally safe services and the provision of cultural safety training should be developed and delivered in partnership with Community Elders for maximum impact.

Palliative care for people with liver cancer is not universal in Australia and there is mounting evidence for early appropriate palliative care to improve quality and duration of life for people with advanced liver disease and HCC (13–15). The inclusion of palliative care physicians as core members of multidisciplinary care teams to facilitate the proactive provision of care has improved access and needs to be continued. However, there are noted disparities in access to palliative care by geography and in culturally diverse communities that must be addressed. Currently there is very little access to palliative care for rural, remote and very remote Aboriginal and Torres Strait Islander people. The needs of these communities are very diverse and dedicated consultation and engagement is needed to identify these needs. Further research and funding are needed to both assess the benefits of palliative care and ensure the services are available and accessible to those who will benefit. Future work should ensure that the HCC management pathway incorporates active decision-making about specialist referral and consideration of early and appropriate involvement of palliative care services. These considerations would optimise clinical and psychosocial outcomes for those people with liver cancer for whom curative treatment is not viable, such as those with decompensated cirrhosis.

The Liver Foundation has developed liver disease training modules for primary care professionals in an effort to improve understanding of the rising burden in the Australian community. In implementing these recommendations, clinicians need to recognise that many patients have multiple causes of liver disease. The Liver Foundation modules could be complemented by focused HCC surveillance training to guide decision-making. Culturally appropriate educational resources should be developed, using co-design approaches involving community leaders, as a priority to tailor services to be culturally and linguistically sensitive and relevant. Targets included in the Third National Hepatitis B Strategy also emphasise the importance of access to information in language. In addition, culturally safe care for Aboriginal and Torres Strait Islander people and culturally and linguistically diverse communities is important to provide, and its delivery should be led by a culturally safe workforce.

PRIORITY ACTION	Provide education to health providers in providing HCC related care in a culturally safe and sensitive way (2yr)
PRIORITY ACTION	Develop culturally sensitive and safe services to provide support post-treatment to liver cancer patients and their carers (2yr)
PRIORITY ACTION	<b>Support and fund resources to meet liver cancer patient needs along the continuum of care</b> (5yr)
PRIORITY ACTION	Explore and address equity issues in access and availability of palliative care to HCC patients (2yr)

## **Ongoing research in liver cancer**

Research efforts in the liver cancer space are expanding over time. The Roadmap has identified ongoing research projects that could contribute to reducing the liver cancer burden in Australia in the short, medium and long term (Appendix C). It is important to note that there is comparatively less research funding and research emphasis on liver disease and liver cancer than in other areas.

The availability of forthcoming results will contribute to the Roadmap priority actions and highlight new areas for action. It will also be essential to expand the focus of the priority actions based on the future results of ongoing research. It is also essential to encourage additional funding and research with a priority on research activities in identifying advanced liver disease and cirrhosis.

## Implementation and measurement

This Roadmap has 26 priority actions which will guide national action to improve liver cancer outcomes. Progress towards achieving the Roadmap will ultimately result in a reversal of the upward trend in liver cancer incidence and mortality in Australia. This progress could first be identified in the liver cancer incidence rates which could stabilise or decrease as prevention and early detection efforts are realised. Access to current linked data is critical in informing the success of these actions. There are ongoing efforts by government and research agencies across Australia to facilitate the mapping of liver cancer risk factors and liver cancer trends. These efforts should be leveraged to measure progress and facilitated by a robust plan for coordinated action. Improvements in access and delivery of treatment and care will be determined by ongoing survival and mortality rates which will take longer to manifest.

Once implemented, it is recommended that the Roadmap be reviewed after the 2-year and 5- year marks. The review should be led by an Expert Advisory Group and include an assessment of the actions against the 2-year and 5-year priorities. Following these reviews, further priorities may be considered to ensure the Roadmap is on track to meet its 10- year ambitions. It is recommended that a Roadmap Monitoring and Evaluation Framework be funded and executed which would also incorporate mechanisms to highlight progress across other identified national strategy actions (e.g., the National Preventive Health Strategy and the Australian Cancer Plan).

## Resources

For more information on liver cancer: https://www.cancer.org.au/cancer-information/types-of-cancer/liver-cancer

For more information on liver cancer data go here: https://ncci.canceraustralia.gov.au/cancer-types/liver-cancer

For more information on strategies mentioned:

- National Preventive Health Strategy https://www.health.gov.au/resources/publications/national-preventivehealth-strategy-2021-2030
- Australian Cancer Plan https://www.canceraustralia.gov.au/australian-cancer-plan
- Hepatitis Strategies https://www.hepatitisaustralia.com/national-strategies
- Optimal Care Pathways: The Optimal Care Pathways (OCPs) provide a framework for the delivery of consistent, safe, high-quality and evidence-based care for people with cancer.
- Optimal Care Pathways have been developed for:
  - hepatocellular carcinoma https://www.cancer.org.au/assets/pdf/hepatocellular-carcinoma-2nd-edition#\_ ga=2.69874327.629183123.1680134707-665290561.1676521403
  - Aboriginal and Torres Strait Islander people with cancer https://www.canceraustralia.gov.au/publicationsand-resources/cancer-australia-publications/optimal-care-pathway-aboriginal-and-torres-strait-islanderpeople-cancer

## References

- 1. Australian Institute of Health and Welfare. Cancer data in Australia [Internet]. Canberra: Australian Institute of Health and Welfare; 2022 [cited 2022 Jul 5]. Available from: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia
- 2. Luo Q, O'Connell DL, Yu XQ, Kahn C, Caruana M, Pesola F, et al. Cancer incidence and mortality in Australia from 2020 to 2044 and an exploratory analysis of the potential effect of treatment delays during the COVID-19 pandemic: a statistical modelling study. Lancet Public Health. 2022 Jun;7(6):e537–48.
- 3. Australian Institute of Health and Welfare. Australian Cancer Incidence and Mortality (ACIM) books: liver cancer [Internet]. Canberra: AIHW; 2018. Available from: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/acim-books
- 4. Huang J, Lok V, Ngai CH, Chu C, Patel HK, Chandraseka VT, et al. Disease Burden, Risk Factors, and Recent Trends of Liver Cancer: A Global Country-Level Analysis. LIC. 2021;10(4):330–45.
- 5. Melaku YA, Appleton SL, Gill TK, Ogbo FA, Buckley E, Shi Z, et al. Incidence, prevalence, mortality, disabilityadjusted life years and risk factors of cancer in Australia and comparison with OECD countries, 1990–2015: findings from the Global Burden of Disease Study 2015. Cancer Epidemiol. 2018 Feb 1;52:43–54.
- 6. Adams LA, Roberts SK, Strasser SI, Mahady SE, Powell E, Estes C, et al. Nonalcoholic fatty liver disease burden: Australia, 2019-2030. J Gastroenterol Hepatol. 2020 Sep;35(9):1628–35.
- 7. Younossi ZM, Marchesini G, Pinto-Cortez H, Petta S. Epidemiology of Nonalcoholic Fatty Liver Disease and Nonalcoholic Steatohepatitis: Implications for Liver Transplantation. Transplantation. 2019 Jan;103(1):22–7.
- 8. Fujiwara N, Friedman SL, Goossens N, Hoshida Y. Risk factors and prevention of hepatocellular carcinoma in the era of precision medicine. J Hepatol. 2018 Mar;68(3):526–49.
- 9. Whiteman DC, Webb PM, Green AC, Neale RE, Fritschi L, Bain CJ, et al. Cancers in Australia in 2010 attributable to modifiable factors: summary and conclusions. Australian and New Zealand Journal of Public Health. 2015;39(5):477–84.
- 10. Australian Government Department of Health. National Alcohol Strategy 2019-2028. Canberra: Commonwealth of Australia; 2019. Report No.: 12045.
- Cancer Council Australia Hepatocellular Carcinoma Surveillance Working Group. Clinical practice guidelines for hepatocellular carcinoma surveillance for people at high risk in Australia. Sydney: Cancer Council Australia; 2023.
- 12. Freeman V, Hughes S, Worthington J, He E, Feletto E. Roadmap to Liver Cancer Control: Scoping Review. Prepared for Cancer Council Australia and the Department of Health. Sydney: Cancer Council NSW; 2021.
- 13. Patel AA, Walling AM, Ricks-Oddie J, May FP, Saab S, Wenger N. Palliative Care and Health Care Utilization for Patients With End-Stage Liver Disease at the End of Life. Clinical Gastroenterology and Hepatology. 2017 Oct 1;15(10):1612-1619.e4.
- 14. Gofton C, Agar M, George J. Early Implementation of Palliative and Supportive Care in Hepatocellular Carcinoma. Semin Liver Dis. 2022;(Oct 18).
- 15. Sabih AH, Laube R, Strasser SI, Lim L, Cigolini M, Liu K. Palliative medicine referrals for hepatocellular carcinoma: a national survey of gastroenterologists. BMJ Supportive & Palliative Care. 2021 Mar 18;

# Appendix A: Expert Advisory Group (EAG), Community Reference Group and Project team

## Expert Advisory Group

Name	Discipline/Expertise	Organisational Affiliation		
Professor Jacob George (co- chair)	Hepatology/Research	Storr Liver Centre		
Dr Nicole Allard (co-chair)	Primary Care/Epidemiology	The Doherty Institute		
Professor Leon Adams	Gastroenterology	University of Western Australia, Department of Hepatology, Sir Charles Gairdner Hospital		
Ms Rosalie Altus	Nursing	South Australian Government		
Ms Catherine Brown	Consumer representation	Consumer		
Associate Professor Jane Davies	Infectious Diseases/Aboriginal and Torres Strait Islander Health	Menzies – School of Health Research, Health Research, Charles Darwin University Royal Darwin and Palmerston Hospitals		
Mr David Fry	Consumer representation	Consumer		
Professor Stuart Roberts	Gastroenterology	The Alfred Hospital, Gastroenterology Dept Monash University Central Clinical School		
Dr Belinda Greenwood-Smith	Primary Care (NT)/ Public Health/ Aboriginal and Torres Strait Islander Health	Northern Territory Government		
Ms Natali Smud (to Oct '22)	Population Health (CALD)	NSW Health		
Associate Professor Patricia Valery	Epidemiology	QIMR Berghofer Medical Research Institute		
Professor Andrew Wilson	Public Health, Health Policy and Epidemiology	Menzies Centre for Health Policy and Economics, Australian Prevention Partnership Centre, Pharmaceutical Benefits Advisory Committee		
Ms Nafisa Yussf	Consumer representation	The Doherty Institute		

## Community Reference Group

Name	Role		
Dr Kate Holliday	Chair		
Ms Katelin Haynes	Chair (to July 2022)		
Dr Thomas Tu	Member		
Catherine Brown	Member		
John Didlick	Member		
Dr Lynne Pezzullo	Member (to Oct 2022)		
Mr David Fry	Member		
Ms Nafisa Yussf	Member		
Mr Russell Shewan	Member		

## Appendix A: Expert Advisory Group (EAG), Community Reference Group and Project team

#### Project team

Name	Discipline/Expertise	Organisational Affiliation
Dr Eleonora Feletto	Epidemiology/ Cancer Control	Daffodil Centre
Ms Claire Latumahina	Public Health	Daffodil Centre
Ms Megan Varlow	Public Policy/ Cancer Control	Cancer Council Australia
Ms Amanda McAtamney	Public Policy	Cancer Council Australia
Ms Deshanie Rawlings	Public Policy	Cancer Council Australia
Ms Cathelijne van Kemenade	Cancer Control	Daffodil Centre
Dr Joachim Worthington	Mathematical Modelling	Daffodil Centre
Ms Suzanne Hughes	Systematic review	Daffodil Centre
Ms Chelsea Carle	Systematic review	Daffodil Centre
Dr Denise Campbell	Systematic review	Daffodil Centre
Ms Victoria Freeman	Systematic review	Daffodil Centre
Dr Susan Yuill	Systematic review	Daffodil Centre
Professor Karen Canfell	Epidemiology/ Cancer control	Daffodil Centre
Mr Paul Grogan	Public Policy/ Cancer Control	Daffodil Centre
Ms Kate Broun	Public Policy/ Cancer Control	Cancer Council Victoria

# **Appendix B**

The Roadmap was developed by Cancer Council Australia to reduce the disease burden, improve outcomes and improve survival for Australians affected by liver cancer through priority actions. Four processes were used to inform the priority actions from 2019 to 2022. These were:

- 1. A scoping review of the literature relating to screening for advanced liver disease and surveillance of patients at high risk of HCC;
- 2. An environmental scan of current service delivery models of care for HCC surveillance in Australia;
- 3. Iterative consultation with the Expert Advisory Group (EAG) made up of key stakeholders in liver cancer control; and
- 4. A Roadmap to Liver Cancer Control Summit and follow-up consultation with key stakeholders which built on the already identified priorities from the scoping review and environmental scan

Further detail on each of these processes can be sought from Cancer Council Australia.

# **Appendix C: Ongoing Research Projects**

Project area	Investigator Group
HepLogic study: primary care and hepatitis screening intervention	Doherty Institute
Early detection of cirrhosis in primary care study using Hepascore RCT	Doherty Institute
Mapping at regional and national diagnosis, in care treatment and liver cancer trends	Doherty Institute
Establishing the burden of hepatitis B in Australia, tracking testing, care and treatment for hepatitis B and C in Australia, generating estimates of mortality and morbidity attributive to hepatitis B and C in Australia (including due to HCC)	Doherty Institute
Prevention of mother to child transmission of hepatitis B including women's understanding	Doherty Institute
System mapping to understand service delivery barriers for hepatitis screening and testing	-
Hepatitis B discrimination and health service access.	Jack Wallace
Identifying the barriers to hepatitis B clinical management: the perspectives of people with hepatitis B.	Jack Wallace
Identifying the structural enablers to the clinical management of people with hepatitis B in general practice: a qualitative investigation	Jack Wallace
The elimination of hepatitis C as a global public health threat.	Jack Wallace
ALT point-of-care diagnostic testing to detect liver disease	Burnet Institute
Cancer information compared to Hepatitis B information to INcreAse hepatitis B testing in Melbourne's Chinese community (CHINA-B study)	Jack Wallace
Creating educational materials in Aboriginal languages.	Menzies School of Health Research
Investigating Treatment Engagement and Monitoring in Hep B-affected communities (ITEM-B study)": Surveying people living with hepatitis B to determine barriers to antiviral treatment and monitoring for progressive liver disease (including HCC)	Storr Liver Centre, HepBCommunity.org, Centre for Social Research
TRACKERx: Biomarkers to predicting relapse in early-stage hepatocellular carcinoma	Harry Perkins Institute, Curtin University, Storr Liver Centre, Sir Charles Gairdner Hospital
Identifying risk factors for HCC in NAFLD cirrhosis	Leon Adams
Trial of non-invasive tests in primary care to identify liver fibrosis.	-
Trial of decision support software to identify people at increased risk of liver fibrosis	-
IC3: Identification of patients at risk for cirrhosis and HCC in primary care	Leon Adams & John Emery
Oncofetal Ecosystem in advanced hepatocellular carcinoma: Implications for identifying Immunotherapy response	Harry Perkins Institute, Curtin University, Storr Liver Centre, Sir Charles Gairdner Hospital
Preventing Liver Cancer – modelling study for advanced liver disease + surveillance	Daffodil Centre
Examining factors associated with failure of current surveillance strategies.	-
Examining the efficacy of HCC surveillance in NAFLD cirrhosis	Leon Adams
ThinkGP education modules	Liver Foundation
Providing care on Country in a primary care setting.	Menzies School of Health Research
PSMA PET scan study for diagnosis of HCC	Siddharth Sood
APRICA program: NSW liver cancer board	Jacob George
National Clinical Quality HCC Registry to measure quality of care	Stuart Roberts
Early implementation of palliative and supportive care in hepatocellular carcinoma	Cameron Gofton
Clinical trials of treatment for patients with HCC	Leon Adams & Stuart Roberts

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