

# State of the Nation in Upper Gastrointestinal Cancers in Australia

**Executive Summary from Final Report to  
Pancare Foundation**

**7 July 2022**





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**Pancare Foundation would like to thank Wheelton Foundation and Highland Foundation for their generous contribution to the development of this report.**



# Executive Summary

Upper gastrointestinal (GI) cancers, including oesophageal, stomach, liver, biliary and pancreatic cancers, are the deadliest group of cancers in Australia today. Combined, these cancers account for approximately one in five cancer deaths (18 per cent) each year.

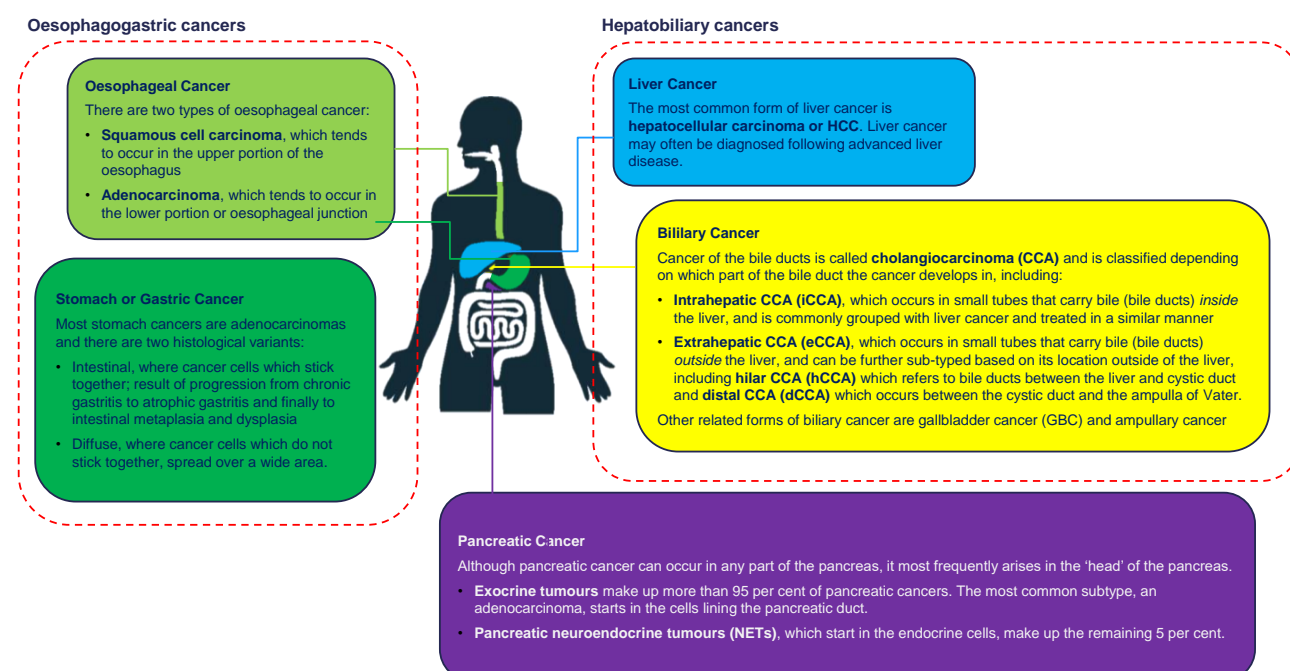
Patients and families impacted by upper GI cancers also experience some of the poorest quality of life outcomes due to the nature of these conditions, which severely impede a patient's ability to eat and absorb nutrients, and often involve treatments such as major organ removal and/or the insertion of feeding tubes. This can lead to debilitating weight loss and fatigue, among other symptoms, which slows recovery and can contribute to clinical depression and anxiety for patients and their families.

While many other cancers have seen step-change improvements in survival and quality of life, upper GI cancer patients and their families sadly have not. Five-year survival rates for upper GI cancers in Australia today remain worse than outcomes for cancer observed in 1975.

This is due in large part to poor funding for upper GI cancer research, which has been and remains inordinately low compared to its burden of disease, both globally and within Australia. It also reflects inconsistent implementation of evidence-based reforms to improve safety and quality of treatment, as well as a lack of standardised pathways for supportive and palliative care.

Upper GI cancers also disproportionately impact Australia's most vulnerable and disadvantaged communities. Indigenous Australians, new migrants, people from culturally and linguistically diverse backgrounds, and Australians from low socioeconomic backgrounds, for example, face significant cultural and social barriers to healthcare that many other Australians are fortunate enough to never contemplate. These barriers include challenges related to poverty, racism, poor health literacy, homelessness, educational disparities, cultural and language barriers, stigma, poor access to basic nutrition and geographic remoteness. These cultural and social challenges often intersect and result in higher risks of cancer. Combined with later and poorer engagement with health services, these communities experience higher rates of cancer incidence and death from upper GI cancers than the general population.

**Figure 1: Overview of upper gastrointestinal cancers**



These extreme treatment and care challenges and inequities make policy reforms and investments to improve outcomes for patients diagnosed with upper GI cancers and their families among the highest priorities for Australian governments and communities today.

## The purpose and method of this report

With survival rates at or below 37 per cent, upper GI cancers need urgent policy focus and investment in research to improve survival outcomes.

In 2017, Australia's Senate Select Committee recommended the development of a national strategy to improve outcomes for low-survival cancers and set an explicit goal to increase 5-year survival rates for low-survival cancers to above 50 per cent before the end of the decade.

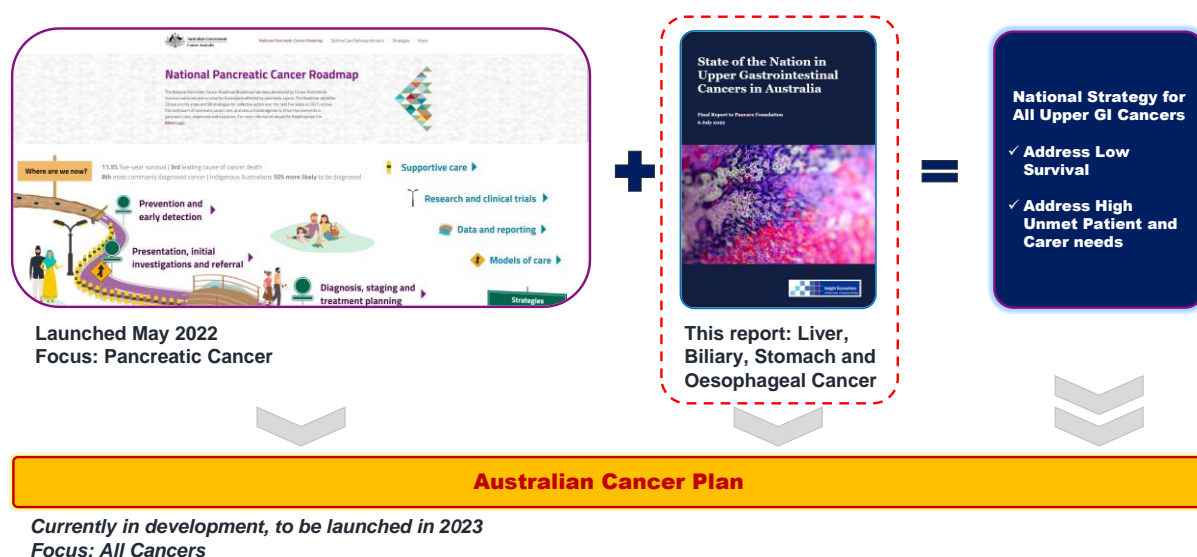
The Australian Government has responded to the call to improve outcomes for low-survival cancers in part through the development of a National Pancreatic Cancer Roadmap, which was released in April 2022; this is a welcome and important first step. The Australian Government is also leading the development of the first-ever Australian Cancer Plan which will articulate a long-term reform plan aimed at improving outcomes for all Australians diagnosed with cancer.

At the same time, no process has been initiated for the other four upper GI cancers — even as liver, biliary, stomach and oesophageal cancers experience among the poorest survival outcomes and quality of life of any cancer in Australia today. With survival rates well below 50 per cent, these cancers need disproportionate, nationally collaborative policy reform and investment to improve outcomes (as called for by the Senate Select Committee in 2017).

Patients and their families need policy action to improve quality and safety in treatment and to improve access to supportive and palliative care services. Patients need to understand their diagnosis, they need help to make informed choices in their treatment, and to receive effective supportive and palliative care services as needed to better manage the physical, emotional, financial and social impacts of an upper GI cancer diagnosis.

In light of the disparity in survival outcomes and the large burden these cancers have on patient and carers, as well as the wider Australian community, Pancare Foundation (Pancare) commissioned the development of a State of the Nation in Upper Gastrointestinal Cancers in Australia report. This report is focused on the needs of these four other upper GI cancers, with the goal of identifying the needs of this underserved cohort and providing a framework for action. The report explicitly considers and seeks to align with other policy work underway, including the development of the Australian Cancer Plan and the National Pancreatic Cancer Roadmap (Figure 2).

**Figure 2: This report addresses the needs of the other four low-survival upper GI cancers – Liver Cancer, Biliary Cancer, Oesophageal Cancer and Stomach Cancer**





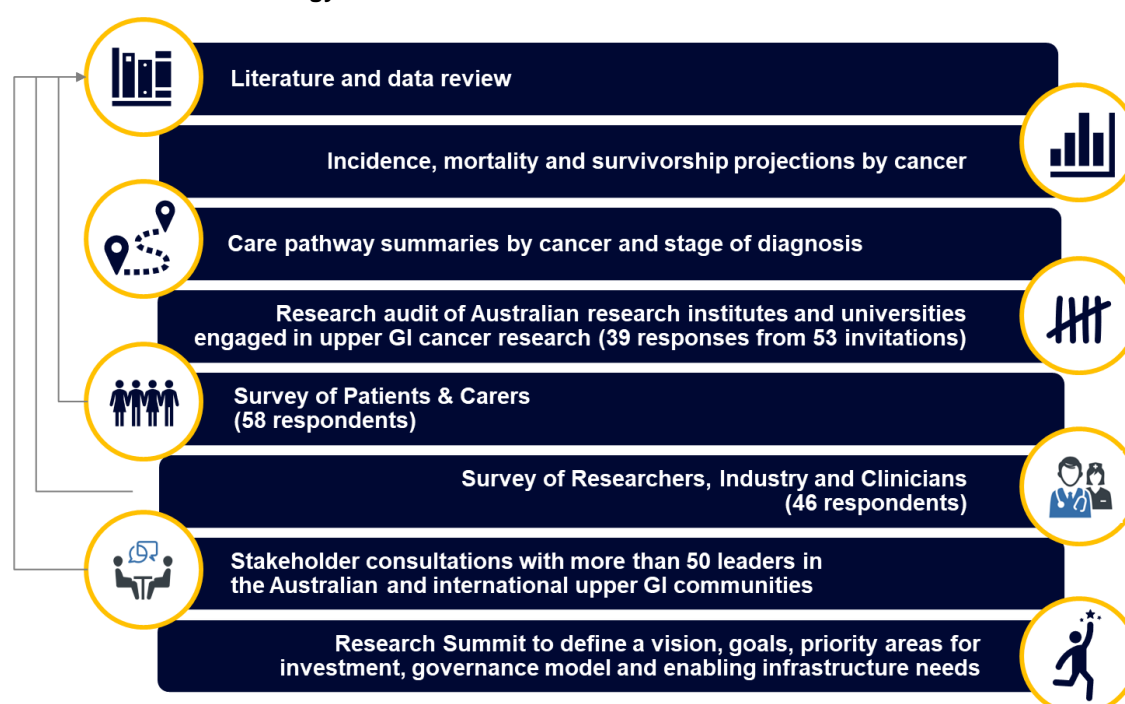
Importantly, this report has been developed from a public interest perspective, with the needs of the patients and carers put first. In this way, the report seeks to present a summary of the upper GI community's ideas and recommendations for change.

Eight major streams of work were undertaken to develop an evidence-based assessment of the challenges and opportunities facing people living with upper GI Cancers in Australia today. These included:

- A survey of Patients and Carers across all upper GI cancers
- A survey of Researchers, Industry and Clinicians across Australia
- Stakeholder consultations with more than 50 leaders in the Australian and international upper GI communities
- A research audit of Australian research institutes and universities engaged in upper GI cancer research, with 39 institutions responding from every state and territory
- A literature and data review
- Incidence, mortality and survivorship projections to 2035
- Care pathway summaries by cancer and stage of diagnosis based on a review of international and Australian clinical guidelines
- A Research Summit with more than 40 stakeholders including patients, carers, clinicians and researchers across every cancer and research discipline, other upper GI charities, clinical trials groups and government to define a vision, goals, priority areas for investment, governance model and enabling infrastructure needs for an Upper GI Cancer Research Mission.

The project was also supported by an Advisory Council comprised of six experts from the upper GI cancer community, which brought together clinician, researcher, consumer, and government perspectives, including Cancer Australia and the Department of Health and Ageing. Pancare Foundation is grateful to the support of this Advisory Council for their strategic guidance and review of this report to ensure alignment with wider policy reform.

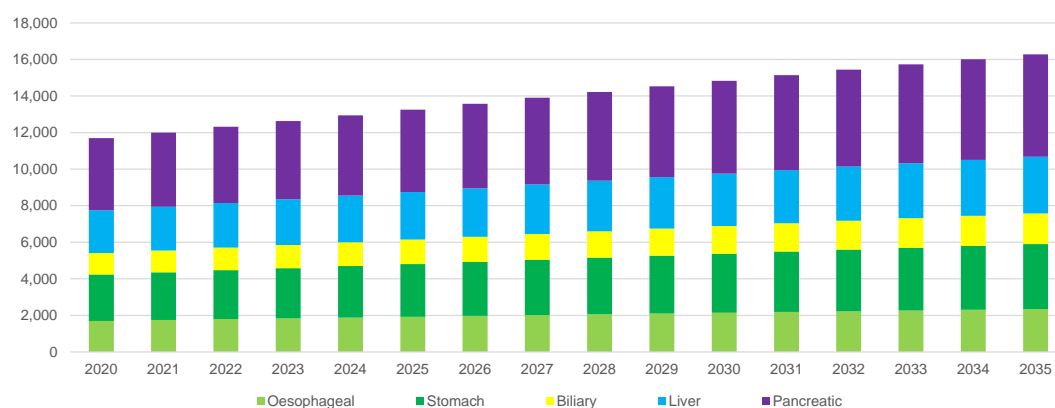
Figure 3: Research methodology



## Australian incidence, mortality and trends in upper GI cancers: more than 200,000 Australians to be impacted by upper GI cancers by 2035

Whilst upper GI cancers are individually rare, together they account for approximately 13,100 new cases of cancer each year. As a result, between 2022 and 2035 (inclusive) more than 200,000 new cases of upper GI cancer are expected to be diagnosed in Australia (Figure 4).

**Figure 4: Incidence (new diagnoses each year) projections (2022 to 2035)**

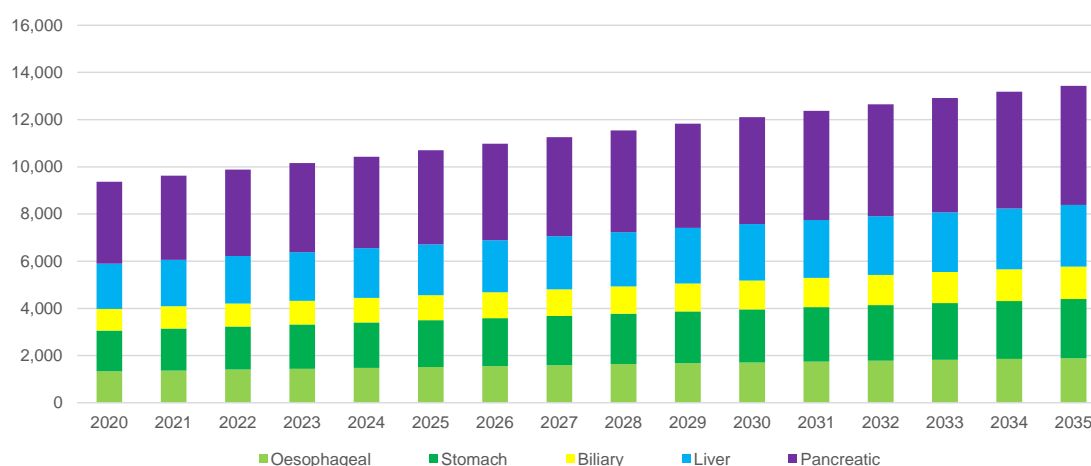


Source: Insight Economics modelling, See Appendix B. Incidence means number of new diagnoses each year.

Due to the poor survival outlook for these patients, approximately 163,000 deaths are expected over that same time horizon (Figure 5), comprised of:

- More than 61,000 deaths due to pancreatic cancer
- More than 32,500 deaths due to liver cancer
- More than 30,000 deaths due to stomach cancer
- More than 23,000 deaths due to oesophageal cancer
- More than 16,400 deaths due to biliary cancer.

**Figure 5: Mortality (deaths from upper GI cancers) projections (2022 to 2035)**



Source: Insight Economics modelling, See Appendix B. Mortality means death from upper GI cancers.

Upper GI cancers are expected to be among the leading causes of cancer death in Australian communities and one of the highest policy priorities for government over this period.

## Challenges and risks for people diagnosed with an upper GI cancer

Poor outcomes for people living with upper GI cancers are a function in part of relatively late detection. People often experience few early symptoms, or symptoms which could be attributed to a number of conditions, and surveillance of underlying medical conditions, such as Barrett's oesophagus or liver disease, which are precursors to upper GI cancers, is often inconsistently implemented.

Upper GI cancers are also complex and difficult to treat, often involving some of the most drastic surgeries in cancer care today and drug therapies that currently have relatively limited effectiveness. The severity of treatment regimes and high supportive care needs of patients and their families necessitate a multidisciplinary approach to treatment and care; however, access to supportive and palliative care services is limited, late and varied across Australia.

Reducing deaths from upper GI cancers will require governments and the upper GI community to address a complex set of issues encompassing health system reforms and investments in research. Figure 6 below summarises the existing and emerging challenges to improving the survival outcomes for upper GI cancers and quality of life for people living with upper GI cancers from diagnosis through treatment to supportive care.

As shown in Figure 6, the challenges and risks for people diagnosed with an upper GI cancer today are many, starting from inadequate primary and secondary prevention of risks, and continuing through to unwarranted variation in treatment and poor access to supportive and palliative care:

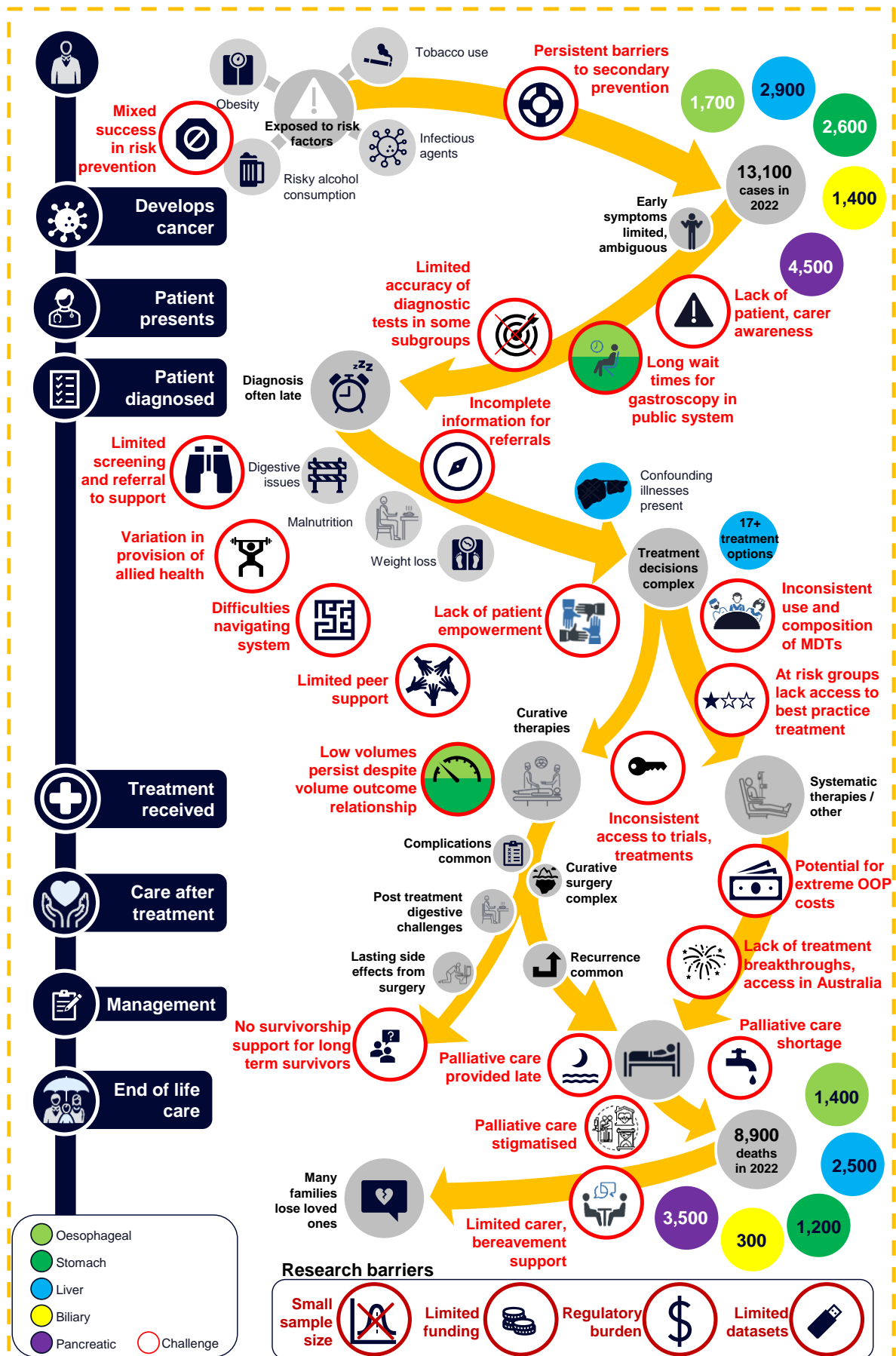
- *Mixed success in risk prevention and early detection* — Australia has performed well overall in reducing key risks for upper GI cancers in the general population, such as reducing tobacco consumption and reducing risks of infectious disease for most Australians. At the same time, key gaps remain. In the general population, there remains a high and increasing trend in obesity, as well as very high excess alcohol use rates. Three out of four Australians are now obese or overweight, making Australia a 'world leader' in obesity, and nearly one in five Australians consume alcohol in excess at rates that lead to a lifetime risk for cancer.

There has also been relatively limited progress in risk mitigation for a number of key 'at-risk' populations, including Aboriginal and Torres Strait Islander communities, new migrants, culturally and linguistically diverse communities, regional Australians, and Australians from low socioeconomic backgrounds. These communities face very significant cultural and social barriers to primary and secondary prevention of cancer. Significant system level challenges include poverty, lack of education, misinformation, misconceptions, stigma, discrimination, racism, employment status, housing status and homelessness, access to healthy food, relative remoteness and rurality, and access to transport. All of these factors can influence access to prevention and early detection services. As a result, risks from tobacco use, alcohol consumption, infectious disease and obesity are all an order of magnitude higher for these communities, notwithstanding some improvements that have been realised over the past decade:

- Indigenous and Asian communities have a 2.8 times greater risk of *H. pylori* infection, which is a risk factor for stomach cancer
- Asian Australians and Indigenous Australians account for 75 per cent of people with hepatitis B, which is a risk factor for liver cancer
- Eight in 10 new cases of hepatitis C in Australia result from the unsafe injecting of drugs, which is a risk factor for liver cancer

(cont'd)

Figure 6: Challenges in upper gastrointestinal cancer prevention, detection, diagnosis, treatment and supportive care today





- Australians from low socioeconomic backgrounds are four times more likely to smoke daily, with one in five Australians in this cohort being a daily smoker
- Indigenous Australians are seven to 10 times more likely to smoke daily, with one in two (52 per cent) of all Indigenous Australians in remote communities being daily smokers
- One in three adult male Indigenous Australians consume alcohol in excess at rates that lead to a lifetime risk for cancer, with 70 per cent of Indigenous patients experiencing alcohol-related cirrhosis compared to 47 per cent of non-Indigenous patients
- Liver disease is growing in low socioeconomic communities at three times the rate of that observed for Australia's most affluent communities (9.4 per cent per annum compared to 3.4 per cent per annum).

Moreover, these communities also consistently present later for treatment and face higher barriers to accessing health services than the general population once they become ill.

- *Persistent barriers and missed opportunities in secondary prevention: liver disease and Barrett's oesophagus* — While evidence shows benefits from surveillance of populations that have higher risk of cancer arising from precursor medical conditions, many patients in these high-risk groups are not under surveillance at the time of their cancer diagnosis. For example, less than half of all patients diagnosed with liver cancer are under any formal surveillance at the time of diagnosis, even though these patients will have often experienced liver disease in advance of their cancer diagnosis. There are also significant inconsistencies in adherence to best practice management of Barrett's oesophagus, which is a precursor medical condition to oesophageal cancer. This frustrates secondary prevention and early detection of these cancers, which can have significant implications for whether a patient is able to access curative treatments. It also contributes to higher, potentially avoidable costs of care in the health system. These issues are likely exacerbated by lack of clinician education and awareness regarding these cancers.
- *Issues in timely diagnosis* — Significant issues exist in the timely diagnosis and appropriate referral of patients to specialist centres. Timely diagnosis can be jeopardised by low patient and clinician awareness of risks and symptoms of upper GI cancers as well as long wait times for diagnosis. For example, median wait times for endoscopy in public care settings fail to meet clinical best practice recommendations. The COVID pandemic has only exacerbated long-term barriers to access for this essential diagnostic tool. Risks were reported to be magnified for regional and remote patients, who can experience lengthy delays to diagnosis and treatment, again potentially frustrating access to curative therapies and leading to poorer survival outcomes. Patients in private settings were reported to be seen rapidly on a consistent basis, which gives rise to the risk of inequities in Australia's universal healthcare system.
- *Barriers to informed specialist referrals* — Treatment of upper GI cancers often involves highly specialised services, which research has shown is best delivered by centres that meet minimum case volume thresholds. In spite of this evidence, many patients continue to be referred to, and treated by, health services that fail to meet these thresholds, which results in poorer survival outcomes compared to high volume centres. Data show that in some jurisdictions as many as one in five patients continue to be treated at low volume centres for oesophagogastric cancer (defined as less than six patients per annum). Available data show that 30- and 90-day mortality rates at low volume centres are more than double those for high volume centres for oesophagogastric services.

- *Variation in treatment* — Staging and treatment planning for upper GI cancers is complex and challenging, with significant implications for the treatment pathway, survival outcome and quality of life for a given patient. Upper GI cancers lack a complete definition of clinical best practice, with gaps in the provision of optimal care pathways for biliary cancer and a lack of Australian clinical guidelines for stomach, oesophageal and biliary cancers. Growing knowledge of best practice has the potential to improve outcomes for patients with upper GI cancers. However, evidence indicates that best practice is not uniformly implemented, resulting in variation in quality of treatment provided. Multi-disciplinary teams were also reported to be inconsistently used, and the composition of these teams are reported to vary significantly between jurisdictions and public-private care settings. This, paired with low case volumes at some hospitals, further contributes to poorer survival outcomes than is possible today given available treatment options. Access to novel and developing treatments is also limited due to scarce access clinical trials.
- *Workforce challenges* — Exacerbated by COVID, workforce shortages limit the ability of health care practitioners to provide best practice care. For example, less than half the number of needed palliative care specialists per 100,000 persons are in the workforce today, which limits capacity to provide early palliative care which would otherwise improve pain management and allow death at home. Similarly, Health Workforce Australia projects significant shortages in available nurses by 2030. Skill shortages can also limit the quality of health care provided to population subsets; for example, through limited cultural responsiveness among health care practitioners.

For both researchers and health care practitioners, limited resourcing can lead to staff departure. Chronically low funding for upper GI cancer research further disincentivises young professionals from entering the upper GI cancer field, in spite of globally leading research output by Australian upper GI research teams, which perpetuates the slow improvement in survival for these low survival cancers.

- *Inconsistent access to supportive care* — Patients and their families experience significant adverse physical, emotional, social and financial effects arising from the diagnosis of cancer and its treatment, which require supportive care services to be delivered in a timely and integrated way alongside other treatments. For example:
  - Over 70 per cent of oesophageal cancer patients experience unintended weight loss and 26 to 75 per cent of patients experience sarcopenia at diagnosis. Patients with upper GI cancer are one of the highest-risk groups for malnutrition, which can affect up to 80 per cent of upper GI cancer patients.
  - More than one in two upper GI cancer patients reported experiencing anxiety in the Patient and Carer Survey. Approximately 50 per cent reported experiencing extreme sadness, fear, and helplessness. Between 40 and 50 per cent of respondents also reported experiencing social isolation, which was exacerbated by the COVID pandemic.
  - More than 80 per cent of carers reported experiencing anxiety, more than 50 per cent reported experiencing social isolation, and more than 40 per cent experienced significant anger.
  - Out-of-pocket costs can also be extreme, particularly where novel therapies are not publicly subsidised. Immunotherapies, for example, can cost over \$100,000, based on a cost of \$11,000 per treatment or roughly \$10,000 per three-week session. Over five per cent of patients in the Patient and Carer survey reported out of pocket costs exceeded \$10,000. These additional costs can put incredible stress on households. In 2017–18, the average equivalised disposable household income was \$1,062 per week; for low-income households this drops to just \$462 per week.

Despite high care needs, patients are inconsistently and infrequently screened for supportive care needs, with unmet needs in psychosocial support services for patients and carers reported to be frequently severe. There is poor awareness of available patient support services, which can crucially support patients to navigate to needed services, and patients often lamented ‘stumbling’ onto patient support late in their treatment and care journey.

Access to allied health services is also a major barrier: a 2022 Australia-wide study found that while dietetic services were available at 92 per cent of services providing upper GI cancer surgeries, only one third of these offered a routine service, and only 44 per cent of services had a routine nutrition protocol or pathway in place. In Victoria, a 2018 study found only 40 per cent of all upper GI cancer patients and only 37 per cent of malnourished patients were receiving dietetics intervention.

Stakeholders also reported little to no access peer support groups for upper GI cancers in Australia, with carers often feeling overwhelmed and invisible. Carers report a lack of communication, stress related to fears of being in hospital or providing the ‘wrong’ care, or of not knowing what to do and the impact of various restrictions such as being unable to accompany their loved ones to health appointments or hospital. There is very limited awareness of any available counselling and support services, and very limited funding for any of these services. Moreover, owing to the poor survival outlook for these cancers, there is no model of care for long-term survivors. Likewise, poor survival contributes to a lack of survivor stories, which has led to reduced visibility of these cancers.

- *Significant variation and barriers to palliative and end of life care* — Early palliative care is recommended by clinical guidelines and understood to be a critical component of safe and quality upper GI cancer care, and yet significant inconsistencies in access and quality were evident from stakeholder consultations, the survey and supporting literature and data. Less than half the number of needed palliative care specialists per 100,000 persons are in the workforce today, and the impacts on patients in regional areas and from disadvantaged backgrounds are amplified through an undersupply of palliative care professionals.
- *Extreme historical underfunding of research* — Upper GI cancers have suffered from long-term underfunding of research by both industry and governments alike, both globally and within Australia, which has contributed to the persistent poor prognosis for these cancers. Despite recommendations for a national strategy to rapidly lift survival outcomes for these cancers within a generation, no significant funding has been invested to date. This is in spite of Australia’s upper GI research community outperforming prestigious research impact benchmarks for health and medical research, including National Health and Medical Research Council funded projects.

Thus, the reform agenda for upper GI cancers is extensive and demanding, requiring significant focus from governments at all levels and collaboration with patient support organisations and professional bodies.

## **Opportunities to improve outcomes for people living with an upper GI cancer and their families**

While there are major challenges to be overcome, there is good reason for hope: significant opportunities are available to substantially reduce the incidence of upper GI cancers, survival and quality of life through policy actions and investment in research.

Evidence presented in this report show these opportunities have the potential to:

- Substantially reduce upper GI cancer incidence, through better primary prevention

- Improve survival in the short run, through earlier detection and improved adherence to clinical best practice today
- Improve quality of life and health services utilisation through empowerment and support of consumers to navigate to the right support when they need it
- Deliver significant breakthroughs in treatment and care through a nationally coordinated approach to research.

### ***Opportunities to reduce the incidence of upper GI cancers***

While some upper GI cancers occur sporadically, there are a number of significant, modifiable risk factors, particularly for liver cancer, that could be substantially reduced in the community today.

For example, the development of a National Strategy for Liver Health could substantially reduce the risks arising from precursor medical conditions, such as hepatitis and cirrhosis, and significantly slow growth in hepatocellular carcinomas. These actions would yield enormous benefits to the community, not only through reduced incidence of liver cancer, but also the incidence and costs of liver disease, which are high and increasing. Complemented with a Roadmap to a Targeted Liver Cancer Screening Program (see below), this offers the potential to improve the early detection of liver cancers and double 5-year survival outcomes based on currently available therapies. The benefits from a National Strategy for Liver Health alone would include:

- Prevent 10,000 hepatitis infections
- Reduce healthcare costs associated with hepatitis infection by \$272 million by 2030
- Reduce cases of cirrhosis by 52 per cent
- Avoid hospitalisation costs associated with the treatment of cirrhosis of \$976 million in NPV<sub>5%</sub> terms over the 2025-2035 horizon
- Reduce the incidence of hepatocellular carcinoma by 47 per cent, preventing between 10,000 and 13,300 cases of liver cancer over the 2025-2035 period depending on the rate of hepatocellular carcinoma
- Avoid hospitalisation costs associated with the treatment of hepatocellular carcinoma patients of between \$323 million and \$427 million in NPV<sub>5%</sub> terms over the 2025-2035 horizon (depending on the rate of hepatocellular carcinoma).

In addition, the development of new models of care for vulnerable and disadvantaged groups, including Aboriginal and Torres Strait Islander people, migrants, culturally and linguistically diverse communities and people from low socioeconomic backgrounds, is needed. In particular these at-risk groups would benefit from new models of primary health care and prevention strategies, with the goal of bringing risks and outcomes for these groups in line with the general population over a 10-year horizon.

### ***Opportunities to improve survival through adherence to clinical best practice***

Significant opportunities to improve outcomes through improved detection, diagnosis, treatment and care also exist. Major opportunities include:

- *A Targeted Liver Cancer Screening Program* — A targeted screening program offers the potential to substantially improve long-term survival. For example, 5-year survival outcomes in Japan are double (44 per cent) those observed in Australia today (22 per cent) as a result of investment in a risk-stratified surveillance program.

- *Improving systems to support referrals to appropriate services and service reform* – Evidence show that 5-year survival for oesophagogastric patients treated at high volume hospitals is between 10 and 60 per cent higher than those treated at low volume health services, but in 2019 nearly one in 10 patients in NSW and one in five patients in Queensland were treated in low volume centres. Stakeholders indicated low volume services remained a challenge in Victoria as well.

Added to these potential programs and service reforms, the development of national cancer data sets, clinical guidelines and clinical care standards represent core, enabling infrastructure needed to drive the uptake of improvements in treatment and care across all care settings. These are critical tools for performance management, which will catalyse the realisation of benefits in survival and quality of life for patients and carers, as well as efficiencies in health services utilisation. Clinical quality registries and national cancer datasets have the potential to deliver a significant return on investment, with benefit cost ratios in the order of 4:1 to 12:1 depending on the scope of the dataset. If a national cancer dataset could realise a one per cent efficiency in cancer care treatment, this could yield net benefits to the community of more than \$1 billion in \$2022 dollars over the 2022-2035 horizon.

***Opportunities to improve quality of life through consistent access to supportive and palliative care for all patients***

More than 200,000 patients and families are projected to be impacted by upper GI cancers before 2035. There are significant opportunities to improve outcomes for these patients and their carers, including:

- Expanding access to consumer navigation and patient support services
- Improving nationally consistent and equitable access to nurse support
- Developing a standardised pathway for supportive and palliative care services.

Data and case studies show that these services not only improve patients' quality of life, but they also improve patterns of health service utilisation, preventing hospital admissions. For example:

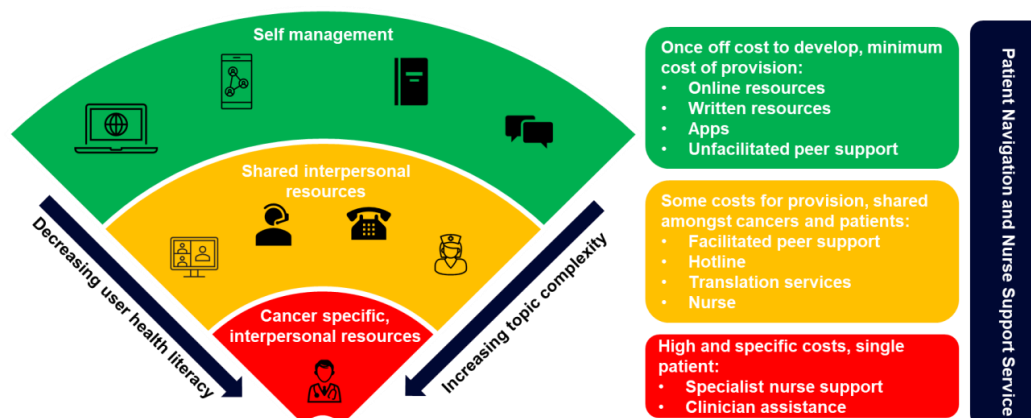
- The introduction of timely, same-day referrals to dietitian services for upper GI cancer patients at a Gold Coast hospital saw a 70 per cent reduction in the number of feeding tube insertions.
- Specialist liver nurses have been shown to reduce demand for outpatient services, prevent emergency department presentations, prevent hospital admissions and improve discharge procedures, delivering a cumulative net saving of \$200k per nurse.
- All.Can Australia estimated consumer navigation support, appropriately designed, could deliver net savings of \$46 million in \$2020, as access to better information helps patients to better manage side effects of treatment, leading to fewer hospitalisations and adverse outcomes.

A national consumer navigation service could be designed to close gaps in consumer information and improve referrals to supportive care services through a mix of printed and online information support services, as well as virtual and in-person support as appropriate (Figure 7). The service could be delivered through a triaged approach, progressing from general care coordinators, to oncology nurses to specialist nurse support.

Because a national consumer navigation service has the potential to deliver improvements to all cancers, this should be implemented as part of the development of an Australian Cancer Plan.



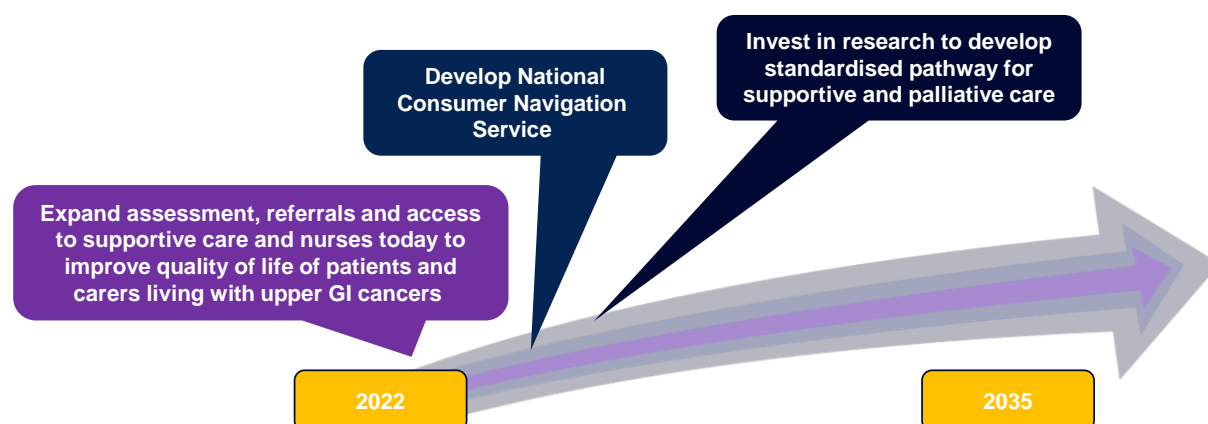
Figure 7: Visualisation of information needs of patients and resource intensity



While the development of a national consumer navigation service is critical, this will take time to develop and will need to be designed in such a way that caters to specific needs of different cancers.

In parallel to the important work of the Australian Cancer Plan, there is an opportunity to improve access to support services for upper GI cancers today. Upper GI cancer patients and families have been shown to have very high unmet needs with limited to no support nationally. Expanding access to patient support services today (Figure 8) offers the potential to improve access to counselling, peer support, financial advice, advanced care planning, physical exercise and nutrition support services.

Figure 8: Enhancing supportive care in the short and long-term



In addition, there is an opportunity to define a nationally equitable approach to nurse funding to ensure all patients enjoy equitable access to nursing support, even if their cancer is relatively rare.

Over the medium-term, support for research to define and optimise a standardised pathway for supportive and palliative care will also see improvements in outcomes over the forward horizon.

### ***Opportunities to realise breakthroughs through a nationally coordinated approach to research***

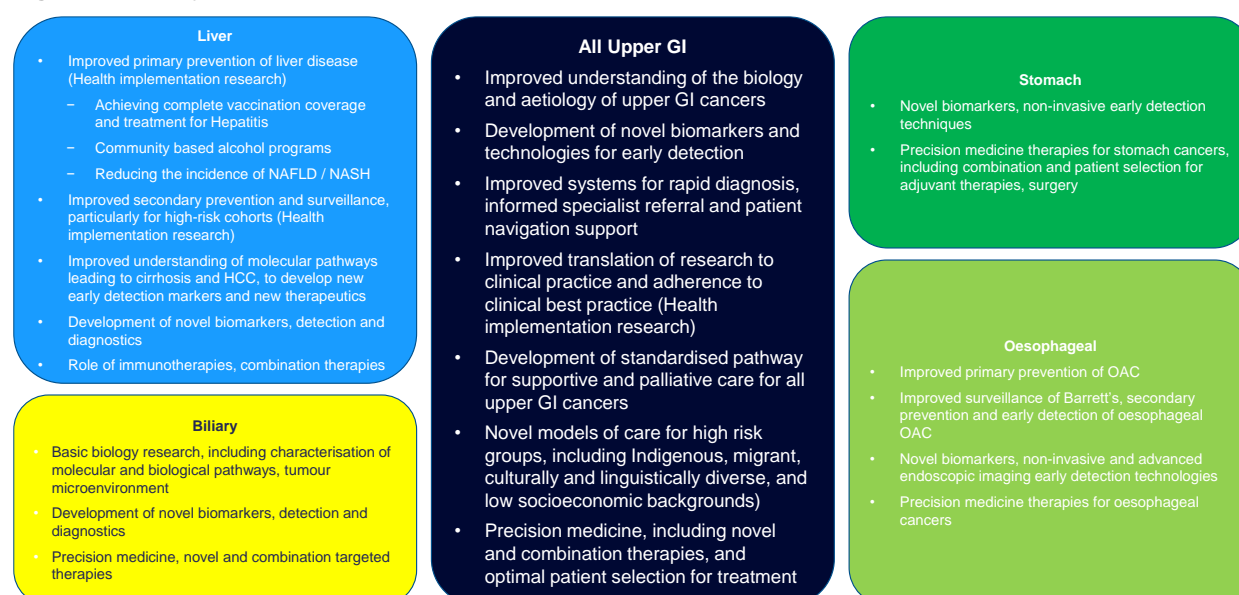
Finally, a nationally coordinated approach to upper GI cancer research, supported by a multi-year funding commitment, has the potential to deliver breakthroughs in treatment and care. This is the approach contemplated by the Senate Select Committee, which called for a

significant, new, coordinated national approach to research across a range of domains to address disparities in survival outcomes. A ten-year Upper GI Cancer Research Mission would provide the core enabling infrastructure and coordination of the wider research community around shared research priorities needed to deliver a step change improvement in outcomes for patients.

Australia's upper GI research community has shown itself to be a consistent, world-leading performer in high impact research within basic biology and aetiology, early detection technologies and treatment domains – outperforming even prestigious National Health and Medical Research Council-funded grant citation benchmarks. Notwithstanding the upper GI cancer research community's outperformance in citation benchmarks, funding for upper GI cancer research has lagged other areas of cancer research, which further contributes to the poor survival outlook for these patients and their families.

The Research Summit for Upper GI Cancers identified a shared vision for the Upper GI Cancer Research Mission, as well as priority areas for research (Figure 9).

**Figure 9: Priority areas for research investment**



Source: Upper GI Cancer Research Summit

## A Plan for Action

Together with upper GI patients and their carers, as well as the wider upper GI research and clinical community, the Pancare Foundation is calling on Australians to help deliver a vision for a future where fewer people are diagnosed with an upper GI cancer, and where upper GI cancer patients live longer, better lives together with their families.

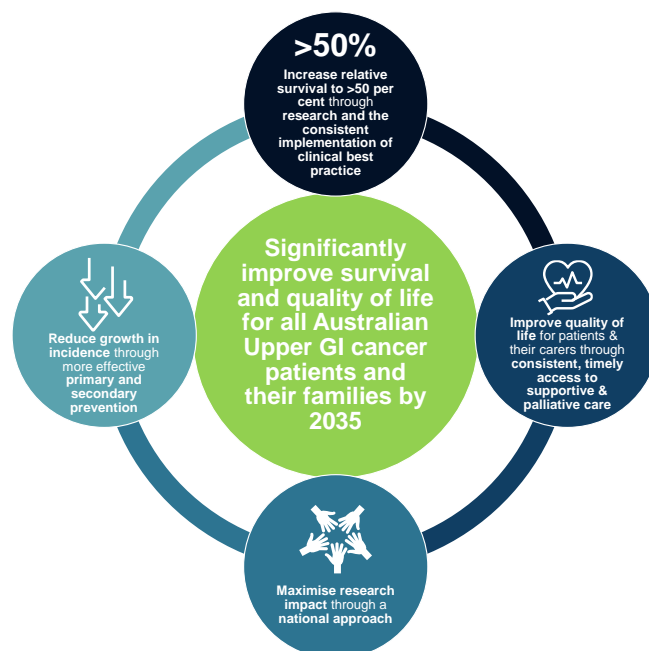
To that end, this report sets out a long-term, 2035 vision statement for upper GI cancers, underpinned by four major goals (Figure 10):

***To significantly improve survival and quality of life for all Australian upper GI cancer patients and their families by 2035, by:***

- Increasing 5-year survival to >50 per cent through the consistent adoption of research as the standard of care and the consistent implementation of clinical best practice***
- Improving quality of life for patients and their carers through consistent, timely access to supportive and palliative care for all people diagnosed with an upper GI cancer***

- **Reducing growth in incidence through more effective primary and secondary prevention**
- **Maximising research impact in upper GI cancers through a national approach.**

Figure 10: 2035 vision and priority areas for action



Critically, this long-term, ‘ambition statement’ for upper GI cancers cannot be achieved through a continuation of the status quo. It will require significant investment and policy reform, with new approaches to collaboration and service delivery to be implemented.

Within each goal statement, a series of actions to improve outcomes are identified to provide a high-level roadmap for implementation. In addition, investments in core enabling infrastructure and activities are identified to support the realisation of all goals and the broader vision. This is summarised in Figure 11 below.

As shown in Figure 11 below, **key strategies to realise the goal of reducing growth in incidence** through more effective primary and secondary prevention include:

- Improve primary prevention of modifiable risk factors
- Develop a National Liver Health Strategy

The **key strategies to realise the goal of increasing relative survival to >50 per cent** through research and the consistent implementation of clinical best practice include:

- Develop a Roadmap to a Liver Cancer Screening Program
- Improve cancer symptom education and awareness
- Establish systems for rapid and informed specialist referral
- Conduct a review of endoscopy services
- Establish a quality framework for upper GI cancers, which comprehensively articulates:
  - Optimal care pathways for every upper GI cancer

- Australian clinical guidelines for every upper GI cancer
- Clinical care standards for every upper GI cancers
- Conduct a review of specialist service delivery in upper GI Cancers.

**The key strategies to realise the goal of improving quality of life for patients and their carers** through consistent, timely access to supportive and palliative care include:

- Expand access to patient support services, including supportive care groups, for patients and carers today
- Establish a standardised pathway for supportive and palliative care in upper GI cancers
- Expand access to patient support services, including supportive care groups, for patients and carers
- Conduct a review Palliative Care Services to improve access, timeliness and quality of care.

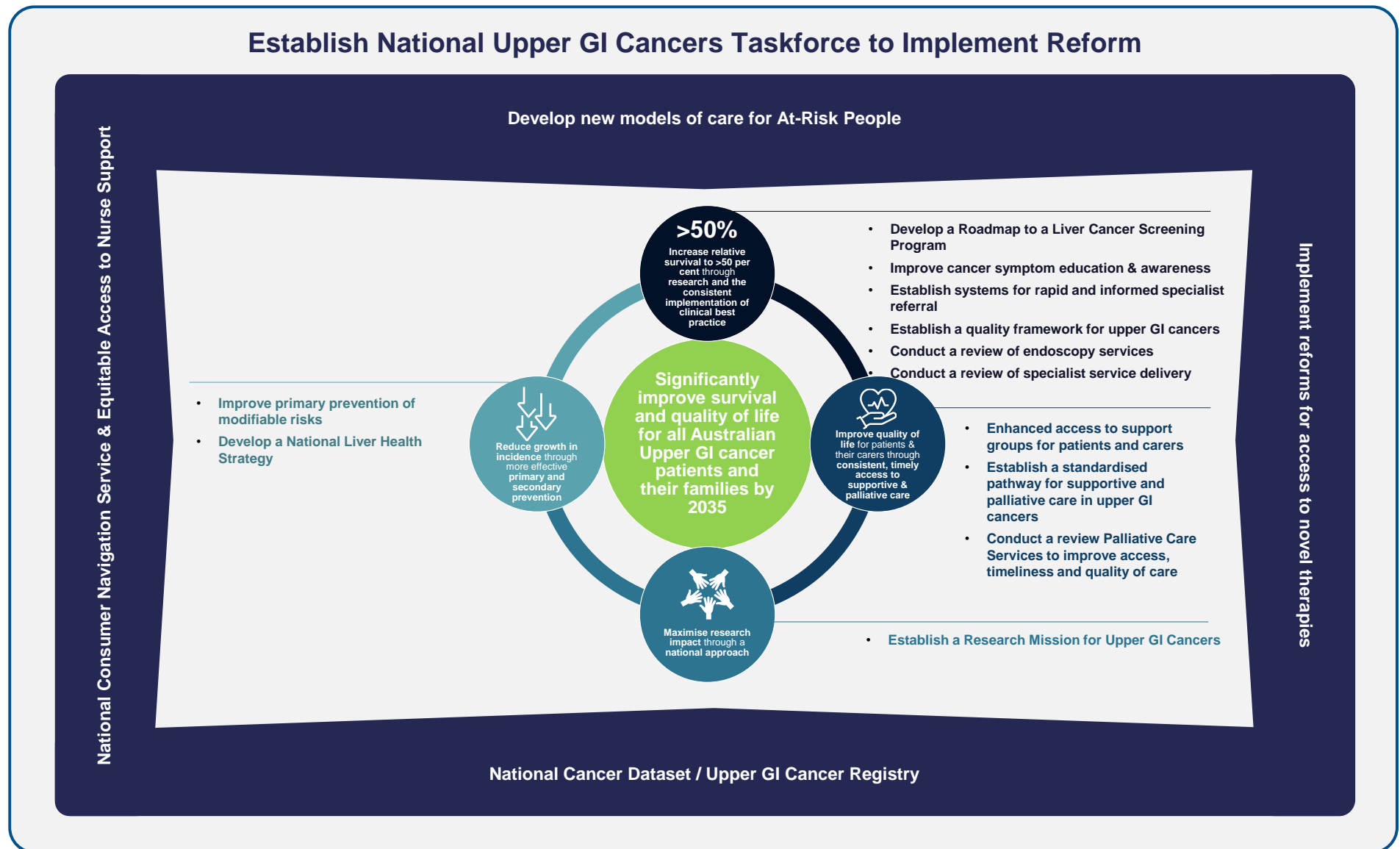
**The key strategy to realise the goal of maximising research impact through a national approach is to:**

- Establish a Research Mission for Upper GI Cancers.

**The core enabling infrastructure and activities** needed to realise the vision include:

- **Establish a National Upper GI Cancer Taskforce**, comprised of federal and state governments as well as consumer, clinician and research leaders to support the national implementation of ‘upper GI-specific’ actions that will not be covered through the core Australian Cancer Plan implementation, which will necessarily be focused on actions and strategies that cut across all cancers.
- **Develop new models of care for at-risk people**, including in particular Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, new migrants, Australians from low socioeconomic backgrounds and regional Australians. These models of care will need to work across multiple Optimal Care Pathway domains, from improved prevention and early detection, through to treatment and supportive care.
- **Develop a National Australian Cancer Data Ecosystem and national expansion of the Upper GI Cancer Registry**, which is fundamental to improving patient outcomes and reducing waste of scarce health resources. The development of a National Australian Cancer Data Ecosystem is expected to be a core priority of the Australian Cancer Plan.
- **Develop a National Consumer Navigation Service and Equitable Approach Nurse Support** based on an evidence-based assessment of need spanning from basic informational support about upper GI cancers through to consumer navigation support services, which could be provided by a range of trained personnel (e.g., not necessarily nurses) through to specialist GI cancer nurse support, which requires specialist knowledge of the supportive care needs of a patient through treatment and beyond. Such a service should leverage existing capability and be delivered as a core priority of the Australian Cancer Plan.
- **Implement reforms to improve access to novel therapies**, which is two-fold: the adoption of recommendations by the Zimmerman Report for a targeted fund to be established for products with rare indications and clinical trials reforms focused on increasing the number of upper GI cancer trials in Australia.

Figure 11: A plan for action to improve outcomes for upper gastrointestinal cancers





## Key partners in implementation

The successful realisation of the long-term ambition for upper GI cancers will depend on sustained partnerships across the upper GI community and with governments at all levels.

To support the implementation of this plan, short-term (2-year) and medium-term (5-year) activities are identified, consistent with the National Pancreatic Cancer Roadmap, which are upper GI specific and not expected to be delivered by other reform work, such as the Australian Cancer Plan or other major reform efforts such as the National Preventive Health Strategy (2021-2030), the National Obesity Strategy (2022-2032), National Alcohol Strategy (2019-2028), or National Primary Health Care 10-year Plan (2022-2032). These actions would be the major focus of the National Upper GI Cancer Taskforce. A series of draft performance indicators have been developed to provide an indication of the timing and magnitude of benefits that could be realised through the effective execution of each action.

**Table 1: Implementation considerations and key partners for success for Upper GI specific actions**

Strategy	Key partners	Action	Timing
<b>Develop a National Liver Health Strategy</b>	Federal Department of Health	Review current federal and state policy approaches to improving liver health	Short term
	The Liver Foundation		
	LiverWell	Refresh National Hepatitis B and C strategies to better target incidence in at-risk groups	Short term
	Hepatitis Australia		
	Cancer Council Australia	Develop National Liver Health Strategy based on evaluation	Short term
	National Aboriginal Community Controlled Health Organisation		
<b>Develop a Roadmap to a Targeted Liver Cancer Screening Program</b>	Federation of Ethnic Communities' Council of Australia	Implement National Liver Health Strategy	Medium term
	Upper GI Cancer NGOs and consumers	Implement refreshed National Hepatitis Strategies	Medium term
	Federal Department of Health	Systematic review of trials of risk-based population screening in terms of (i) evidence about the benefits and harms for different risk groups and (ii) their potential translation to the Australian health setting.	Short term
	The Liver Foundation		
	Hepatitis Australia		
	LiverWell		
	Cancer Council Australia		
	National Aboriginal Community Controlled Health Organisation	Design or adapt and test existing approaches to targeted surveillance	Short term
<b>Conduct a review of endoscopy services</b>	Federation of Ethnic Communities' Council of Australia	Implement a targeted surveillance program	Medium term
	Primary Health Networks	Identify existing decision support tools for assessment of signs and symptoms of upper GI cancers	Short term
	Australian College of Rural and Remote Medicine		
	Upper GI Cancer NGOs and consumers	Implement upper GI cancer decision support tools	Medium term
	Federal Government	Identify barriers and enablers for gastroscopy for public patients by state, territory and region	Short term
<b>Conduct a review of endoscopy services</b>	State Governments		
	Australian Commission for Safety and Quality in Health Care	Implement reforms to improve access	Short term
	Gastroenterological Society of Australia	Implement systems of rapid and seamless referral into specialist care	Medium term
	Upper GI Cancer NGOs and consumers		

Strategy	Key partners	Action	Timing
<b>Establish a quality framework for upper GI cancers including, OCPs for every cancer, clinical guidelines for every cancer and a clinical care standard for upper GI cancers</b>	Federal Department of Health Cancer Australia State Governments Australian Commission for Safety and Quality in Health Care Australian and New Zealand Gastric and Oesophageal Surgery Association Australian and New Zealand Hepatobiliary Association Gastroenterological Society of Australia Palliative Care Australia National Aboriginal Community Controlled Health Organisation Federation of Ethnic Communities' Council of Australia Upper GI Cancer NGOs and consumers	Develop an OCP for biliary cancer	Short term
		Establish baseline metrics for quality standard metrics (e.g., access to MDT, discussion of clinical trials, screening for supportive care, early access to palliative care, and define PROMs/PREMs)	Short term
		Implement a clinical care standard for upper GI cancers to measure and promote adherence to minimum quality standards established through the clinical guidelines.	Medium term
		Implement a clinical care standard for upper GI cancers to measure and promote adherence to minimum quality standards established through the clinical guidelines.	Medium term
		Establish working definition of 'high-volume centre' in order to map and categorise existing centres	Short term
<b>Conduct a review of specialist service delivery in upper GI Cancers</b>	Federal Government State Governments Australian and New Zealand Gastric and Oesophageal Surgery Association Australian and New Zealand Hepatobiliary Association Gastroenterological Society of Australia Upper GI Cancer NGOs and consumers	Create a registry of treatment centres that are considered high-volume/specialised in upper GI cancer treatment across each state and region	Short term
		Develop national standards of clinical capability for high-volume, specialist centres in upper GI cancers	Medium term
		Develop a nationally agreed minimum dataset and framework for data collection, collation and reporting on clinical quality indicators and national benchmarking	Medium term
		Develop structured pathway for supportive care services	Short term
<b>Establish a standardised pathway for supportive and palliative care in upper GI cancers</b>	Federal Government State Governments Royal Australian College of General Practitioners Primary Health Networks Australian College of Rural and Remote Medicine Upper GI Cancer NGOs and consumers	Enhance provision and strengthen awareness of supportive care services through improved funding of patient support	Short term
		Identify current status and gaps in access to coordinated supportive care	Short term
		Design or adapt and test standardised supportive and palliative care pathway	Short term
		Develop and implement educational modules on best-practice supportive and palliative care for upper GI cancers	Short term
		Strengthen linkages between primary health professionals and specialist multidisciplinary teams	Medium term
		Implement standardised supportive care pathways	Medium term
		Promote awareness of upper GI supportive care services to health professional	Medium term

Strategy	Key partners	Action	Timing
		Expand access to available patient support services	Short term
<b>Enhanced access to support groups for upper GI patients and carers</b>	Upper GI Cancer NGOs and consumers Federal Government State Governments	Review Australian and international best practice models for support groups in upper GI cancers, including peer support and professionally-led support groups	Short term
		Develop and implement first generation support network for upper GI cancers	Short term
		Promote support networks with health professionals	Short term
		Review support network strategy and refine as required	Medium term
		Establish Strategic Advisory Group for mission	Short term
<b>Upper GI cancers Research Mission</b>	Federal Government (MRFF, Dept Health) State Governments Research and clinical leaders from cross section of cancers, research fields and disciplines Patients and carers, Upper GI cancer NGOs National Aboriginal Community Controlled Health Organisation FECCA Multicultural Health Collaborative.	Agree upon funding model, policies and principles, and core enabling infrastructure	Short term

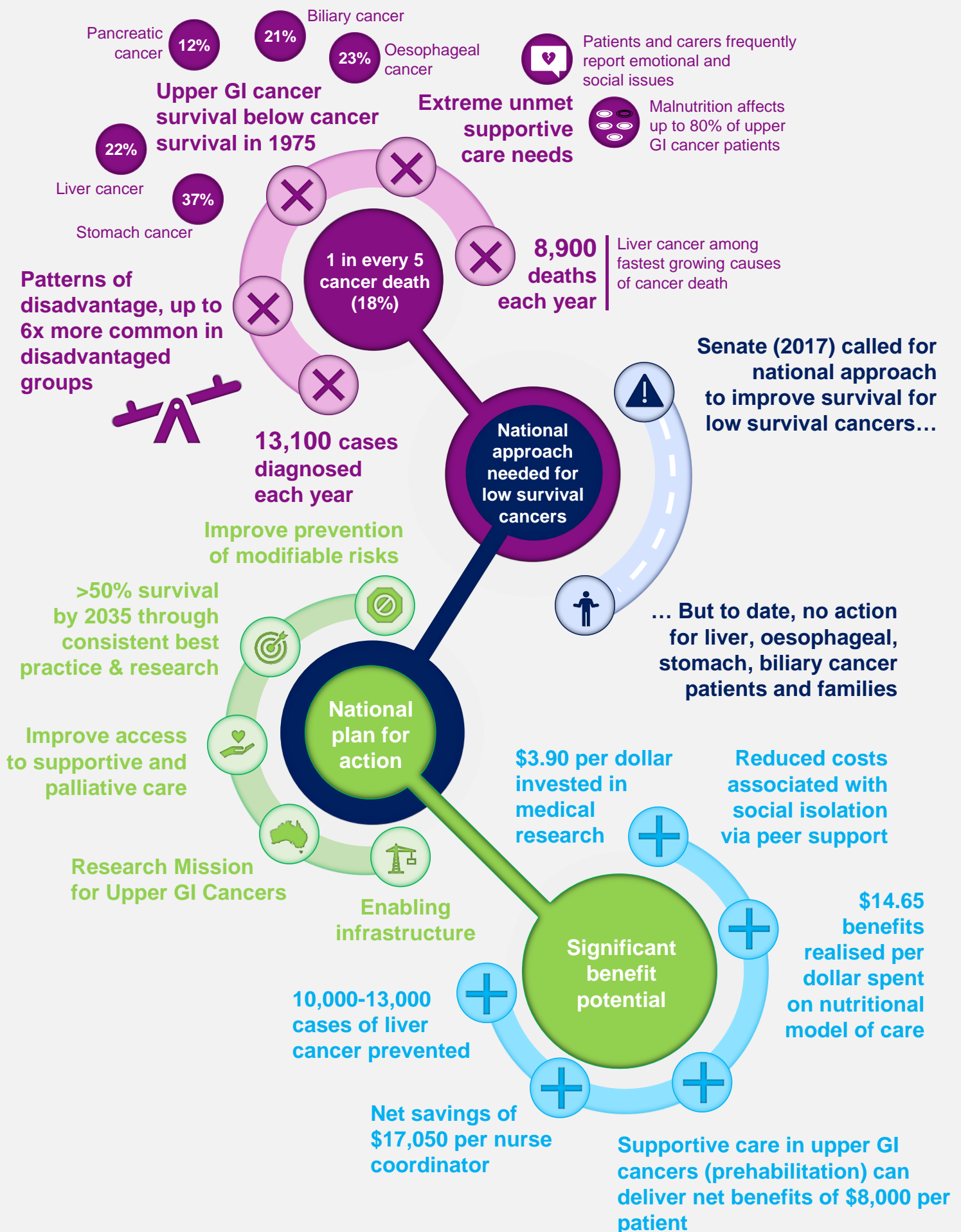
## Immediate next steps for action

Working together, with long-term funding support from governments and the NGO sector, this plan has the potential to deliver significant improvements for patients and their families, as well as the wider health care system and to Australian community. This plan will prevent disease and cancer in the community, substantially increase long-term survival, and improve quality of life for patients and their families today through consistent and enhanced access to supportive care.

The Pancare Foundation calls on the Australian Government to:






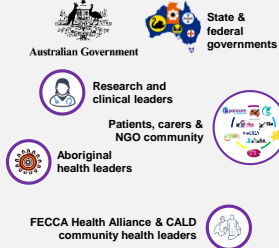



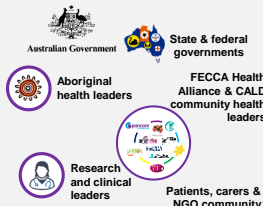
- Improve outcomes for patients immediately by funding increased access to patient support services
- Ensure nationally equitable access to specialist nursing support for Upper GI cancers
- Fund an Upper GI Cancer Research Mission
- Respond to the recommendations of this report with a plan for expanding the reform agenda for Pancreatic Cancer to include Upper GI Cancers, reflecting their similarly low survival outcomes and high unmet supportive care needs
- Establish a National Upper GI Cancer Taskforce to support interjurisdictional policy reform and investment for upper-GI specific actions alongside the development and delivery of the Australian Cancer Plan and other reform work.

# State of the Nation in Upper Gastrointestinal Cancers



# State of the Nation in Upper Gastrointestinal Cancers

**Immediate next steps needed to reach a future where fewer people are diagnosed with an upper GI cancer, and where upper GI cancer patients live longer, better lives together with their families**

Action		Partners	Rationale
<b>Fund Patient Support Services</b> 	<b>Improve outcomes for patients immediately by funding increased access to patient support services to close gaps in information and access to supportive care</b>		<ul style="list-style-type: none"> <li>Limited services nationally leading to high unmet needs for patients and families</li> <li>Consumer navigation at national level will take time to establish, specialist help is needed today</li> <li>Service can support 6,500 upper GI cancer patients and carers by 2027</li> <li>Decreasing costs per case reflecting scale</li> </ul>
<b>Ensure Equitable Access to Nurses</b> 	<b>Ensure nationally equitable access to specialist nursing support for Upper GI cancers nationally</b>		<ul style="list-style-type: none"> <li>High unmet supportive and palliative care needs for upper GI patients</li> <li>A nationally equitable approach, nurse-to-patient ratios consistent with breast, prostate, melanoma cancers</li> <li>Nurse support can lead to savings, up to \$200,000 per year per nurse</li> </ul>
<b>Fund an Upper GI Cancer Research Mission</b> 	<b>Nationally approach to research collaboration to address challenges and deliver high impact outcomes</b>		<ul style="list-style-type: none"> <li>National approach for low survival cancers recommended by Senate</li> <li>National collaboration limited</li> <li>\$5.80 for every dollar invested in Australian investigator led clinical trials</li> <li>\$3.90 for every dollar invested in medical research</li> </ul>
<b>Commit to reform for all Upper GI cancers</b> 	<b>Leverage and expand the reform agenda for pancreatic cancer to include upper GI cancers, due to low survival outcomes &amp; high unmet needs</b>		<ul style="list-style-type: none"> <li>National approach for low survival cancers recommended by Senate</li> <li>No low survival cancer left behind</li> <li>Efficiencies from whole upper GI approach</li> </ul>
<b>Establish an Upper GI Cancer Taskforce</b> 	<b>Establish a National Upper GI Cancer Taskforce to support policy reform and investment for upper GI actions</b>		<ul style="list-style-type: none"> <li>Ensure upper GI-specific reforms are implemented in timely and nationally consistent way alongside Australian Cancer Plan reforms</li> </ul>



