UPPER GI CANCER REGISTRY

MONASH University

Upper Gastrointestinal Cancer Registry

Five Year Report

Data from 2019-2023




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Foreword

Professor John Zalcberg
UGICR Coordinating Principal Investigator

I am delighted to present the first publicly available aggregate report of the Upper Gastrointestinal Cancer Registry (UGICR). As a clinical quality registry, the UGICR has now matured over five years, and this report documents its achievements from 2019 to 2023. It summarises data collected by UGICR data collectors from patients diagnosed with pancreatic, oesophagogastric (oesophagus and stomach), primary liver cancer and biliary cancer (pilot only).

The UGICR provides an unparalleled, real-world dataset that enables exploration of current patterns of care, capturing detailed information on diagnosis, treatment, and outcomes. Given the poor prognosis associated with these cancers, understanding current practice and focusing on improving outcomes is an urgent priority. The registry is designed to systematically measure quality of care, assess compliance with national and international guidelines, and drive improvements for patients. This report presents outcomes from 20 public and private health services across the UGICR's four modules.

Over this period, the UGICR has developed a strong clinical and applied research program, supporting more than 15 associated studies that leverage the data and infrastructure established through this quality-of-care initiative. It has proven to be an ideal platform for research into upper gastrointestinal cancers, including clinical trials, biobanks, and studies focused on quality of care and quality of life. The registry also facilitates recruitment for registry-based randomized controlled trials and longitudinal studies. These value-added studies have been supported by State and Federal Government grants and industry partners, highlighting the critical role of real-world data in informing clinical practice and pharmaceutical development.

None of these achievements would have been possible without the ongoing support of registry participants and their families, site Principal Investigators, UGICR steering committee and working party members, consumer representatives, and the UGICR academic, operational, and data collection teams. I am excited to see the UGICR continue to mature and expand as a vital resource for improving care for people with pancreatic, oesophagogastric, biliary, and primary liver cancers. This includes the continued provision of benchmarked reports to participating sites and stakeholders to drive quality improvement.

Professor John Zalcberg, AO
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Inaugural Tony Charlton Chair of Oncology
UGICR Coordinating Principal Investigator
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Executive Summary

The Upper Gastrointestinal Cancer Registry (UGICR) was established in 2015 with seed funding from the Department of Health and Human Services Victoria and the Pancare Foundation. It serves as a clinical quality registry (CQR) dedicated to monitoring and improving the quality of care for individuals with upper gastrointestinal (GI) cancers in Australia.

The UGICR consists of four modules that collect diagnostic, treatment, and outcome data on individuals newly diagnosed with pancreatic, oesophagogastric (OG), biliary, and primary liver (hepatocellular carcinoma) cancers. Data is gathered from both public and private healthcare settings in Victoria and New South Wales for the pancreatic and oesophagogastric modules. The launch of each module followed a staged approach, with the pancreatic cancer module being the most developed. The pilot for the oesophagogastric cancer module has been completed, and data collection is now underway at Victorian sites. The biliary cancer module pilot has also been completed, but data collection is temporarily on hold due to limited resources. The primary liver cancer module successfully commenced in 2021 with collection in Victoria, New South Wales and most recently South Australia and Queensland.

The UGICR operates within the School of Public Health and Preventive Medicine in the Faculty of Medicine, Nursing and Health Sciences at Monash University, adhering to the high ethical standards and research practices upheld by the School. The registry holds National Mutual Acceptance (NMA) ethical approval (HREC/15/MonH/134) and strives to align with the Australian Commission on Safety and Quality in Health Care recommended principles for CQRs. These include the secure collection and protection of patient data, collaboration with clinical groups to design quality indicators, and comprehensive data analysis to assess the appropriateness and effectiveness of care. This report presents five years of data collection from 1/1/2019 to 31/12/2023 where available for the specific modules, and reports aggregate quality indicator (QI) outcomes for the pancreatic and OG modules.

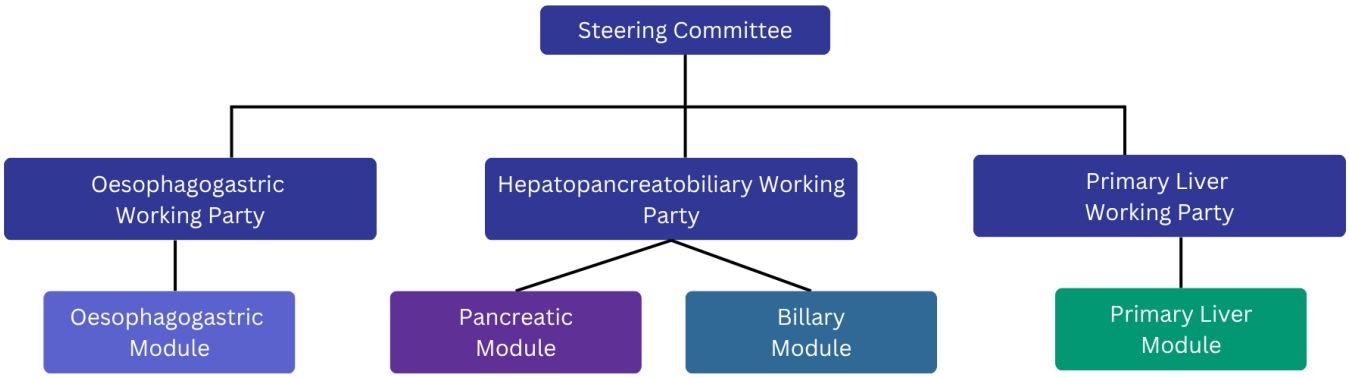
Glossary

Term/Abbreviation	Definition
ACSQHC	Australian Commission on Safety and Quality in Health Care
AGITG	Australasian Gastro-Intestinal Trials Group
BCLC	Barcelona Clinic Liver Cancer
CA 19-9	Cancer Antigen 19-9
CCI	Charlson Comorbidity Index
CEUS	Contrast-Enhanced Ultrasound
CQI	Clinical Quality Indicator
CQR	Clinical Quality Registry
CT scan	Computed Tomography scan
ECOG	Eastern Cooperative Oncology Group
FNA	Fine Needle Aspiration
HBC	Hepatitis C Virus
HBV	Hepatitis B Virus
HCC	Hepatocellular Carcinoma
HER2	Human Epidermal growth factor Receptor 2
LI-RADS	Liver Imaging Reporting and Data System
MAFLD	Metabolic associated fatty liver disease
MDM	Multidisciplinary meeting
MELD	Model for End-stage Liver Disease
MPCCC	Monash Partners Comprehensive Cancer Consortium
MRFF	Medical Research Future Fund
MRI scan	Magnetic Resonance Imaging scan
NAFLD	Non-alcoholic fatty liver disease
NEMICs	North Eastern Melbourne Integrated Cancer Services
NHMRC	National Health and Medical Research Council
NMA	National Mutual Acceptance
NOS	Not otherwise specified
OG	Oesophagogastric
PEI	Pancreatic Enzyme Insufficiency
PERT	Pancreatic Enzyme Replacement Therapy
PET scan	Positron Emission Tomography Scan
PPCT	Pancreatic Protocol CT
PPPD	Pylorus-preserving Pancreatico Duodectomy
PREMs	Patient Reported Experience Measures
PROMs	Patient Reported Outcome Measures
RRCT	Registry-based Randomised Control Trial
RD	Registry derived
REDCap	Research Electronic Data Capture
RRCT	Registry-based Randomised Control Trial
SMICs	Southern Melbourne Integrated Cancer Services
T1DM/T2DM	Type 1/Type 2 Diabetes Mellitus
TACE	Transarterial Chemoembolisation
TARE	Transarterial Radioembolisation
UGI	Upper Gastrointestinal
UGICR	Upper Gastrointestinal Cancer Registry
VCA	Victorian Cancer Agency

Research Methodology and Governance

The UGICR is governed by a Steering Committee and three clinical working parties: the Hepatopancreatobiliary Working Party, the Oesophagogastric Working Party, and the Primary Liver Working Party (Figure 1).

Figure 1: UGICR governance structure



UGICR Recruitment Pathway

Patient recruitment commences following the appointment of a local investigator at a site, receipt of ethics approval covering that site, and hospital governance approval. The method for identifying eligible patients will vary by jurisdiction and site, depending on the source of Upper GI cancer notifications. These may include, but are not limited to, state-based cancer registries, hospital or surgical centre medical records, treatment and outpatient clinic lists, pathology reports, private clinician medical records, and other government databases. The recruitment process and schema are outlined below (Figure 2).

Upon receiving a notification, the registry will review the patient's medical record to confirm vital status, diagnosis date, and histopathological, cytological, or clinical confirmation of Upper GI cancer. Patients diagnosed on or after January 1, 2016, will be eligible. If a patient is deemed eligible and is not deceased, they will be sent a Participant Information Letter and Booklet. The date of dispatch will be recorded in the UGICR database.

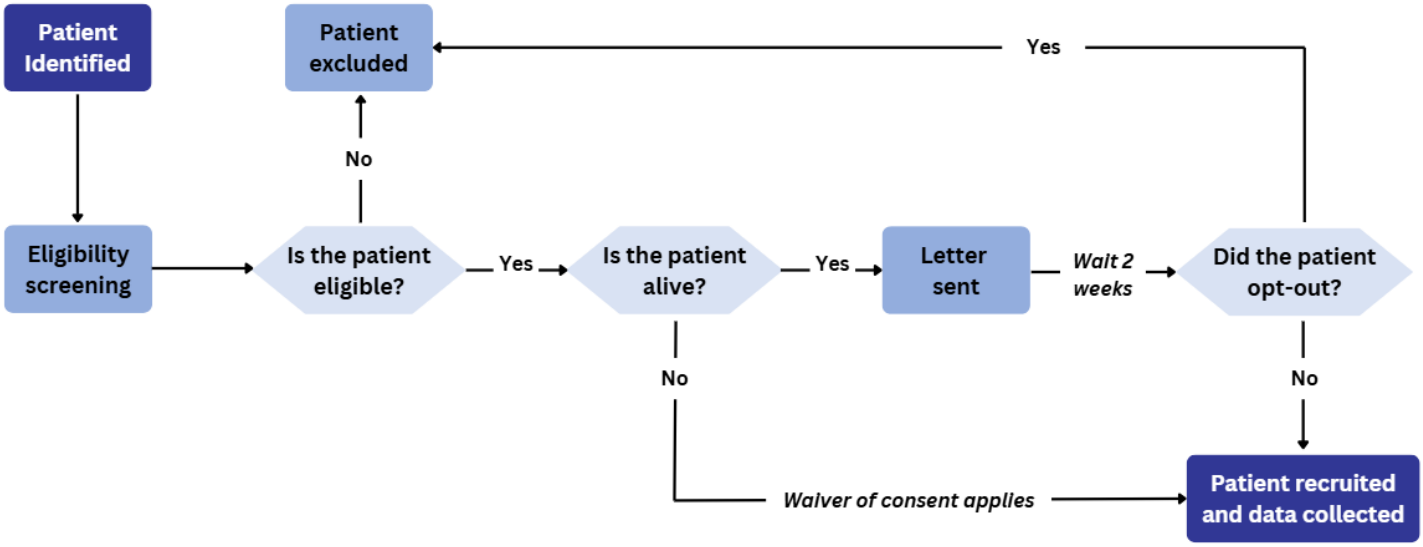
Inclusion criteria:

- All newly-diagnosed patients presenting to a participating hospital with a confirmed primary oesophageal, gastric, primary liver, biliary and pancreatic cancer of the histological types specified in each module (some histological types will be excluded).
- Patients with an initial diagnosis date after 1st January 2016.
- Patient is 18 years of age or older.

Exclusion criteria:

- Specific histological types or tumour sites will be excluded from the registry, e.g., neuroendocrine tumours of the pancreas.
- Patients who were diagnosed before 1st January 2016.
- Patients who have contacted the registry to opt out.

Figure 2: UGICR workflow



Registry Engagement

The UGICR has active data collection occurring at public and private hospitals across Australia, with ongoing plans for expansion (Table 1).

Table 1: UGICR participating health services

Victoria	
• Albury-Wodonga Health • Alfred Health • Austin Health • Bendigo Health • Cabrini Health • Eastern Health • Epworth Healthcare • Goulburn Valley Health • Grampians Health (previously Ballarat Health) • Jessie McPherson Private Hospital • Latrobe Regional Health	• Melbourne Health • Monash Health • Northern Health • Peninsula Health • Peter MacCallum Cancer Centre • South West Healthcare • St Vincent's Hospital • St Vincent's Private Hospital • Warringal Private Hospital • Western Health
New South Wales	
• Calvary Mater Newcastle • Chris O'Brien Lifehouse • John Hunter Hospital • Royal North Shore Hospital • Prince of Wales Hospital	• Prince of Wales Private Hospital • Bankstown-Lidcombe Hospital • Campbelltown Hospital • Liverpool Hospital • Royal Prince Alfred Hospital
Queensland	
• Royal Brisbane and Women's Hospital	• Sunshine Coast Hospital
South Australia	
• Royal Adelaide Hospital	

A total number of **5,129** participants have been recruited to the UGICR between registry commencement in 2016 and the end of 2023. Table 2 shows the number of patients per module with data collection completed between 2019-2023 and analysed for this report.

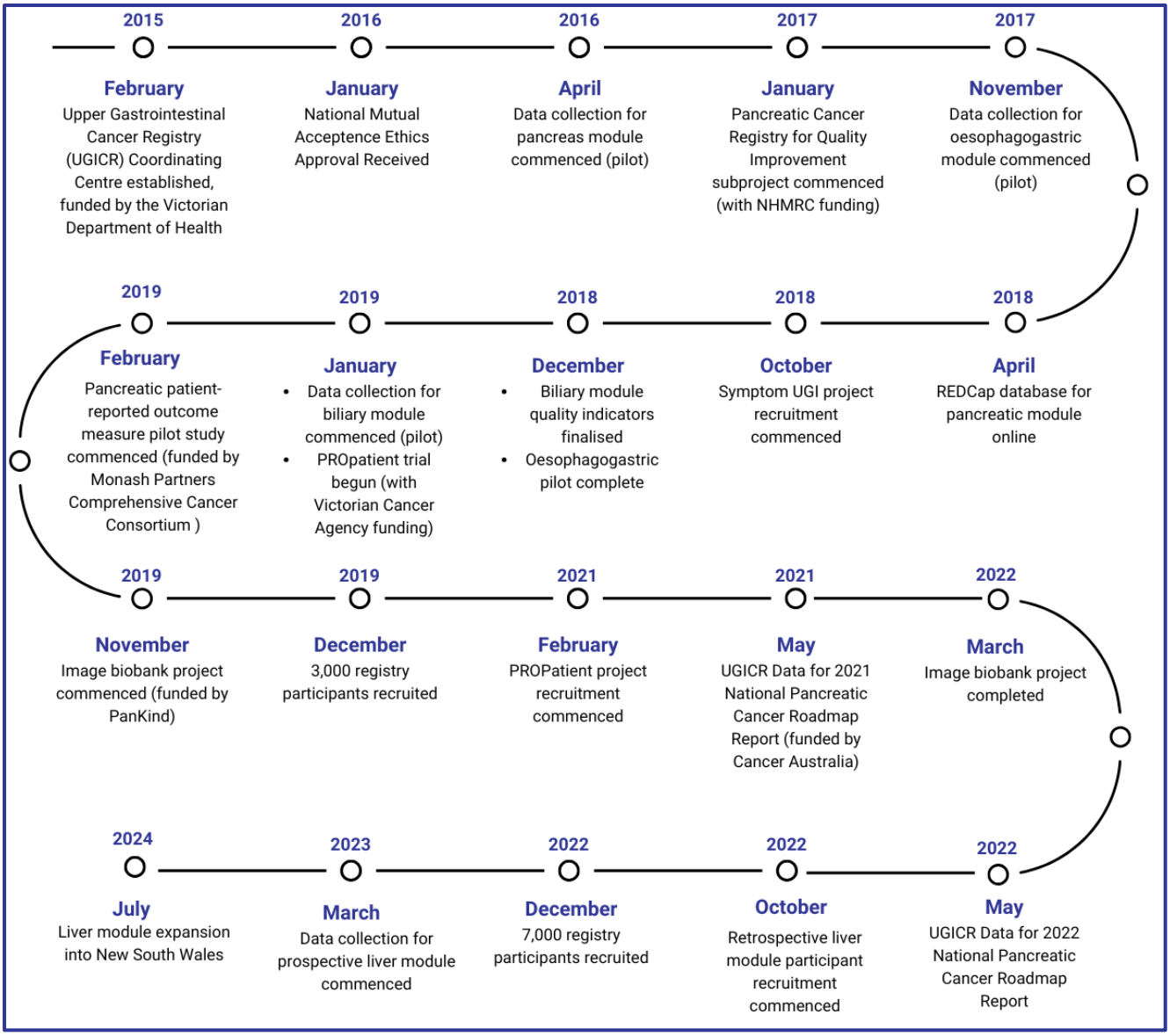
Table 2: Number of patients recruited to the UGICR between 2019 and 2023

Module	Number recruited (exc. Opt out)	Opt out rate (%)
Pancreas	2,632	2.40
Oesophagogastic	1,931	3.30
Biliary	142	1.62
Liver	424	4.35
All sites (modules)	**5,129**	**2.73**

Milestones

Figure 3 showcases the key milestones reached by the UGICR over the past decade.

Figure 3: UGICR milestones



Pancreatic Module

Foreword

Dr Dan Croagh, Pancreatic Module Clinical Lead

The desire to develop a clinical quality registry for pancreatic cancer became the impetus for the development of the UGICR within the Monash School of Public Health and Preventive Medicine under the guidance of Professor John McNeil. The pancreatic module was the first module created within this registry and was inaugurated in 2015.

A Delphi process involving experts in pancreatic cancer from across Australia was convened in 2015 to develop and refine the clinical quality indicators that were selected for inclusion within the registry. These indicators addressed all aspects of the disease from diagnosis to palliative care. After successful grant funding from Victorian Department of Health, the registry obtained ethics and governance approval for data collection in over 80% of hospitals in Victoria (later extending into NSW to include the six largest health services) and began collecting data in 2016. The registry elected to adopt a centralised model of data collection with the hope that this would ensure complete data collection across all stages of disease, minimise selection bias and avoid reliance on busy clinicians for data collection. The registry is linked to the National Death Index to allow assessment of survival outcomes.

The UGICR registry has collected data on over 6,000 pancreatic cancer patients over the last 9 years with complete data collection on over 3000 patients. The registry has also provided an invaluable platform for clinical research culminating in the recently completed PROpatient study which is a randomised control trial examining the impact of addressing patient reported outcomes using nurse led centralised care co-ordination.

The Registry has been funded by contributions from the Victorian Department of Health, research grant funding and industry support. As we look toward the future, changes to the structure of the registry, including increased use of administrative data, the use of artificial intelligence and increased involvement of participating sites are being considered to minimise costs and ensure sustainability of this important resource.

Dr Daniel Croagh
MBBS, PhD, FRACs
Hepatobiliary and Pancreatic Surgeon
Director of Research Monash Medical Centre
Senior Lecturer, Monash University

Demographics and Disease

72 years
median age at diagnosis

53%
were male

54%
were born overseas

85%
English as preferred language

77%
live in metropolitan areas

- **63%** of patients had no documented diabetes at diagnosis. **30%** were diagnosed with Type 2 Diabetes Mellitus and **1%** with Type 1 Diabetes Mellitus (Figure 4).
- **32%** of patients were never smokers at diagnosis, with **13%** current smokers and **25%** ex-smokers. **27%** of patients did not have smoking status documented in their medical records (Figure 5).
- **51%** of tumours were located at the head or uncinate process of the pancreas, **29%** in the body and **4.9%** in the neck (Table 3).

Figure 4: Diabetes at diagnosis

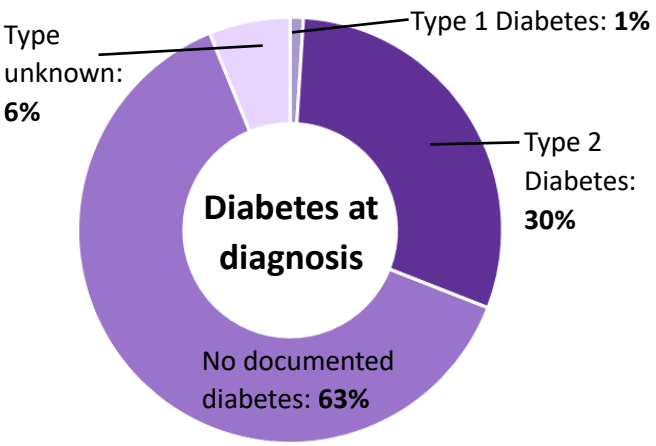
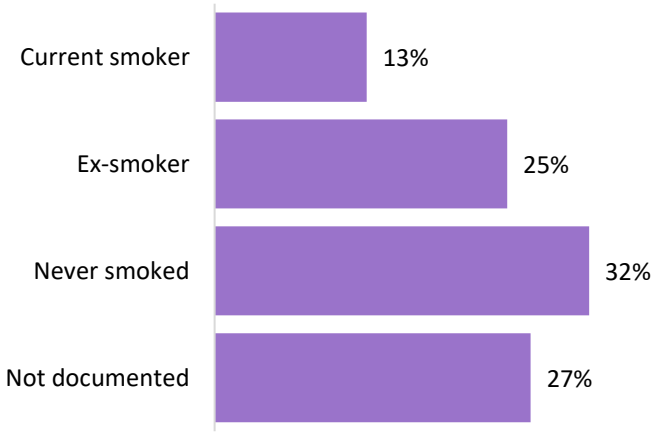


Figure 5: Smoking status



- **84%** of patients underwent a tissue biopsy, with **50%** confirmed to have malignant histology and **8.9%** showing suspicious but non-diagnostic findings.
- Among those with staging completed, **17%** were diagnosed with resectable cancer, **11%** with borderline resectability and **65%** with unresectable cancer.

Figure 6: Tumour resectablility

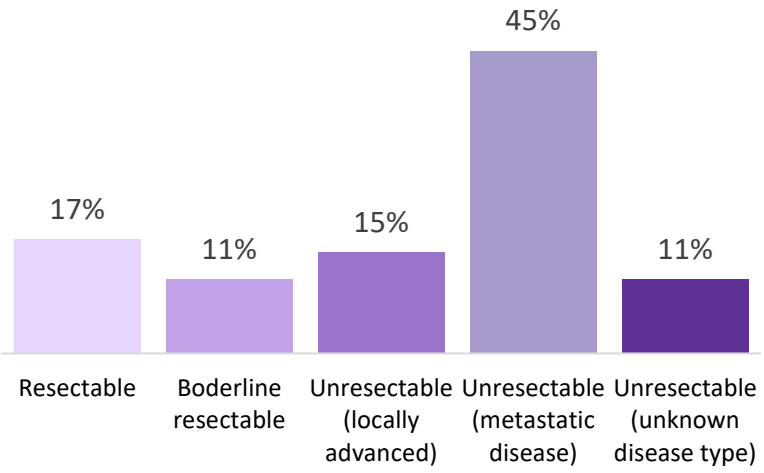


Figure 7: Tissue biopsy

Table 3: Pancreas tumour location

Head & uncinate process	51%
Body & Tail	29%
Periampullary & Ampullary	5.7%
Pancreas NOS*	5.7%
Neck	4.9%
Distal bile duct	2.0%
Not documented	2.1%

**NOS=not otherwise specified*

Patterns of Care

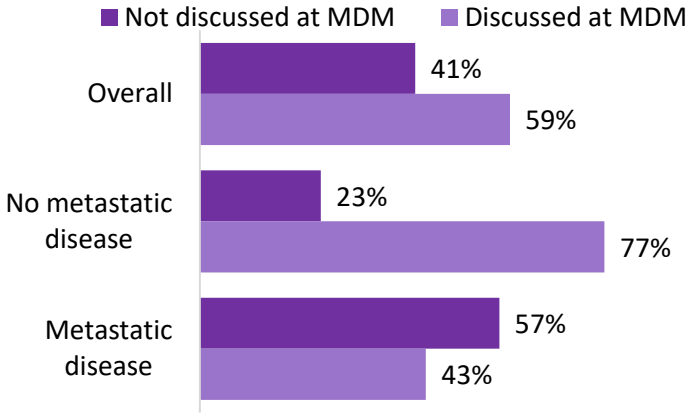
26% had a surgical resection

56% had chemotherapy

16% had radiotherapy

35% had no treatment

Figure 8: Discussion at a multidisciplinary meeting (MDM)



- **41%** of patients had documented discussion at a multidisciplinary team meeting (MDM), Figure 8.
- Among patients with metastatic disease, **43%** were discussed at a MDM, compared to **77%** of patients without metastatic disease (Figure 8).
- **26%** of patients underwent a pancreatic resection.
- The most common type of pancreatic resection was a Whipple or modified Whipple (PPPD) resection (**69%**) followed by a distal pancreatectomy (**13%**) and total pancreatectomy (**4.2%**), Table 4.
- In **11%** of patients who had a resection, the resection was abandoned intraoperatively.

Table 4: Type of pancreatic resection

Whipple resection or PPPD*	69%
Distal pancreatectomy	13%
Abandoned resection	11%
Total pancreatectomy	4.2%
Sub-total pancreatectomy	1.9%
Central pancreatectomy	0%
Resection type not documented	0.3%

**Pylorus-preserving pancreatico-duodectomy (PPPD)*

ECOG performance status was documented for **40.1%** of patients, of whom **75%** had a score of <2.

85% of patients had their CA19-9 measured.

22% of patients with metastatic disease had a pancreas protocol CT or an MRI.

73.7% of patients who did not have chemotherapy were seen by a medical oncologist.

79.3% of patients underwent treatment (resection, chemotherapy or radiotherapy) within 60 days of referral.

77% of patients were referred to a dietitian.

85% of patients had a referral to palliative care.

12% of patients enrolled in a clinical trial following diagnosis.

21% of patients had neoadjuvant chemotherapy prior to surgery.

60% of patients had adjuvant chemotherapy after surgery.

3% of patients had neoadjuvant radiotherapy before surgery.

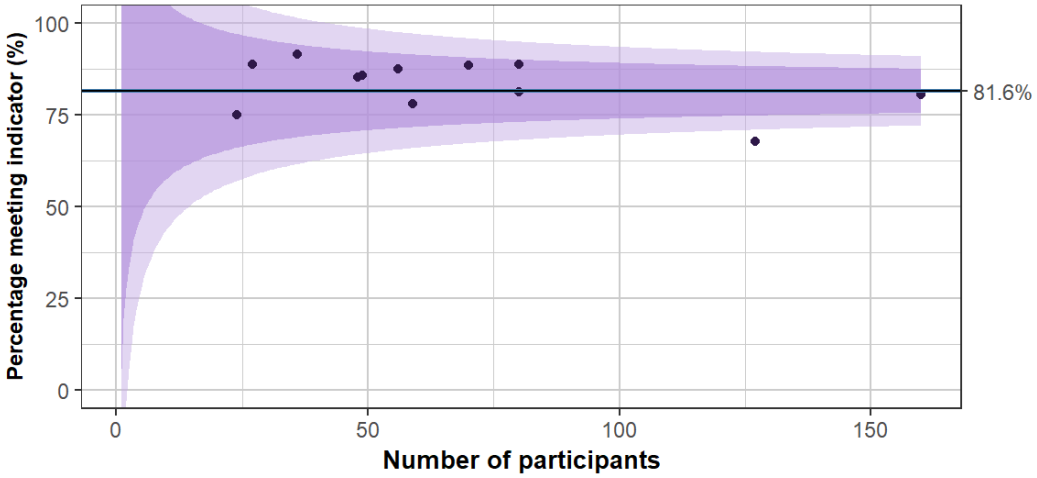
6.6% of patients had adjuvant radiotherapy after surgery.

Key Quality Indicators for Pancreatic Cancer

The UGICR collects and reports on data relating to 27 clinical quality indicators (CQIs) for the pancreatic module. These CQIs have been developed through a modified Delphi process. They are risk adjusted and benchmarked against the UGICR cohort. Four CQIs are illustrated below for descriptive purposes.

Participating sites will receive an annual CQI report, allowing them to compare and benchmark their performance against other UGICR sites. When a site is identified as a potential outlier, a validation process is initiated, and the site is encouraged to review its internal practices. For a full list of pancreatic cancer CQIs and their definitions, please refer to **Appendix 1**. The CQI's presented in this aggregate report are essential to improve the quality of care received by patients.

How to interpret a funnel plot

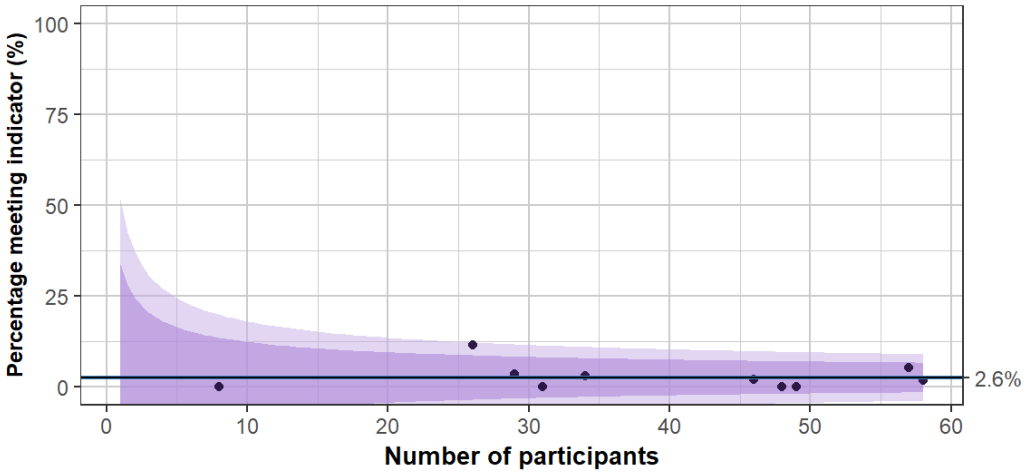


When interpreting funnel plots (see example plot above), the horizontal axis (x-axis) shows the number of patients at each site. The vertical axis (y-axis) measures the performance of each site according to the CQI. Each site is represented by a black dot. The horizontal black line represents the overall mean (percentage meeting the indicator) of observed participants for all health services combined. Sites within the dark purple shaded area indicate their performance is within 95% (two standard deviations) of the overall mean. Sites whose performance is within 99.8% (three standard deviations) of the overall mean are within the light purple shaded area. Sites outside of the shaded area, fall outside the 99.8% performance.

CQI: Proportion of surgical patients who died within 30 days of surgical resection

The overall mean proportion of patients that died within 30 days of surgical resection was **2.6%**, with most health services having their performance within 95% of the overall mean (Figure 9).

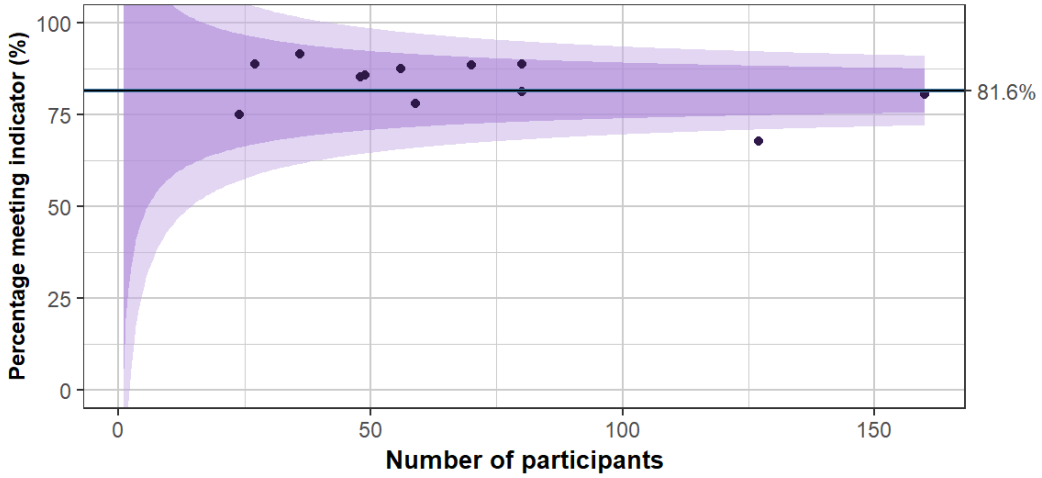
Figure 9: Patients who died within 30 days of surgical resection



CQI: Proportion of patients with metastatic disease who was referred to palliative care

The overall mean proportion of patients with metastatic disease who were referred to palliative care was **81.6%**, with most health services having their performance within 95% of the overall mean (Figure 10).

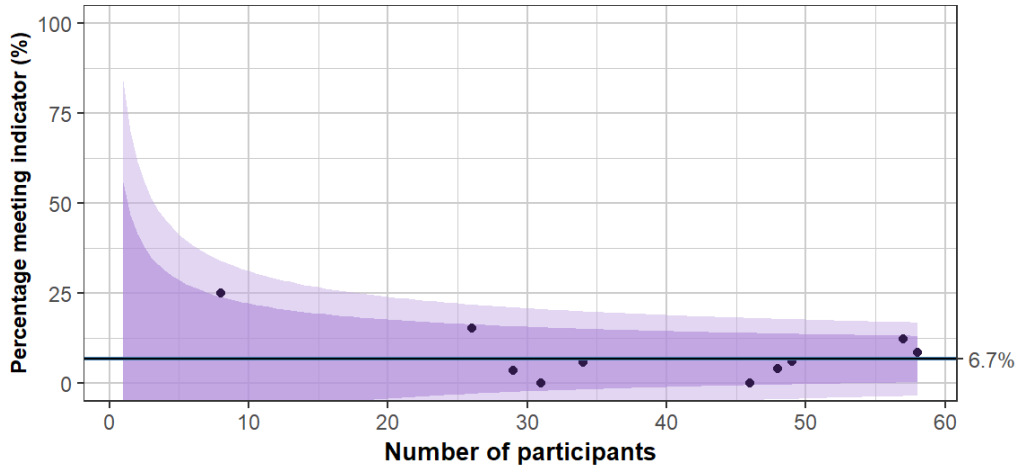
Figure 10: Patients with metastatic disease referred to palliative care



CQI: Proportion of patients who required re-operating following a surgical resection

The overall mean proportion of patients who required reoperating following surgical resection was **6.7%**, with most health services having their performance within 95% of the overall mean (Figure 11).

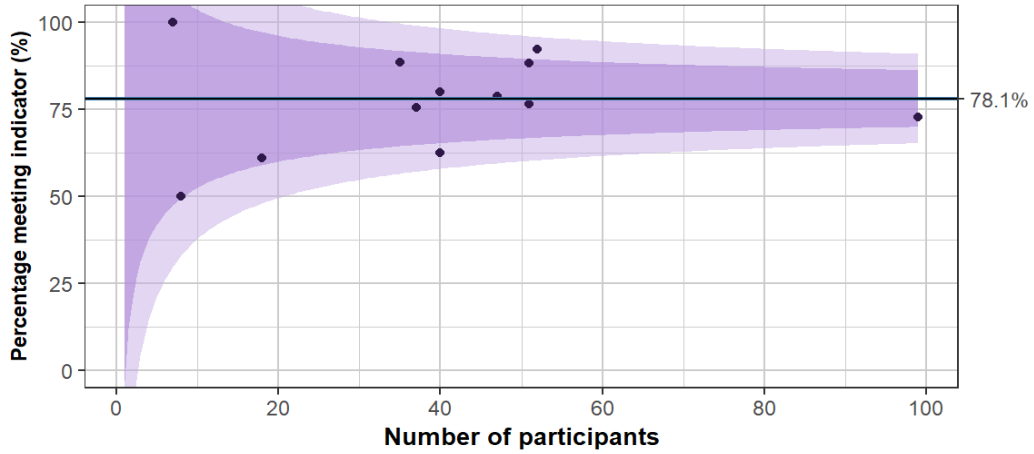
Figure 11: Patients requiring re-operating following surgical resection



CQI: Proportion of patients who had time from referral to definitive treatment within 60 days

The overall mean proportion of patients that had a referral to definitive treatment within 60 days was **78.1 %**, with most health services having their performance within 95% of the overall mean (Figure 12).

Figure 12: Patients who had a referral to definitive treatment within 60 days

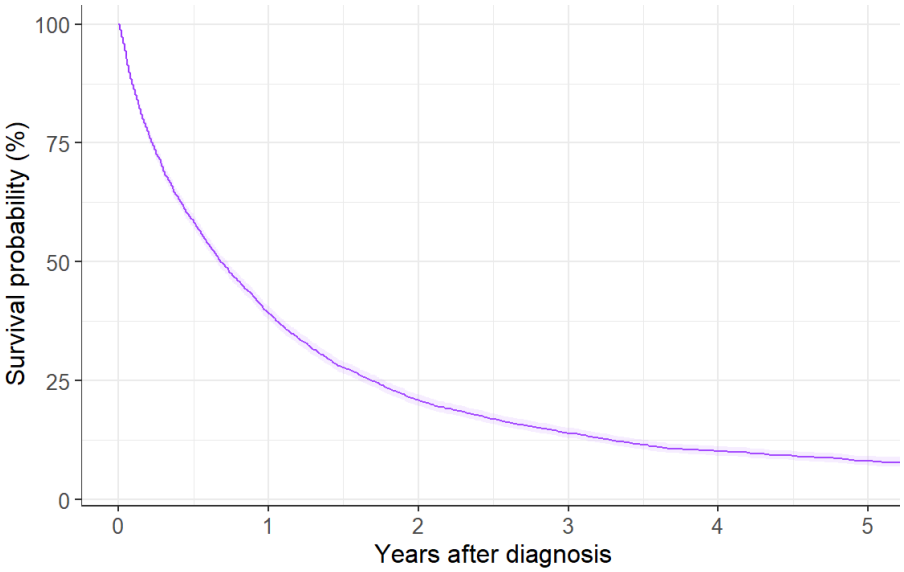


Survival of Patients with Pancreatic Cancer

Overall survival

The median survival for patients with pancreatic cancer was 6.8 months (Figure 13).

Figure 13: Overall survival for pancreatic cancer patients

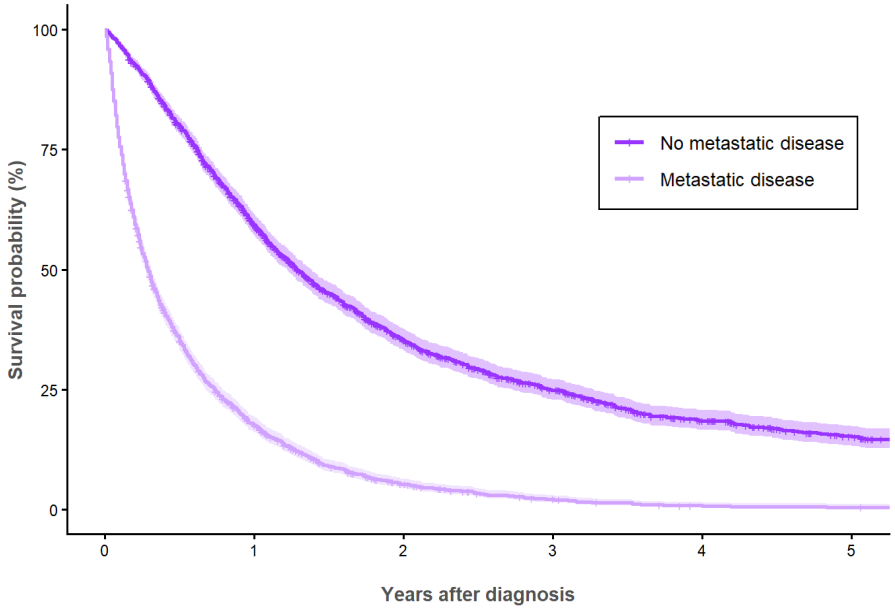


Median survival:	6.8 months
1-year survival:	39%
2-year survival:	21%
5-year survival:	8.2%

Survival by clinical stage

For patients with metastatic disease, the median survival rate was 2.9 months. This was lower compared to patients with non-metastatic disease (Figure 14).

Figure 14: Survival by non-metastatic and metastatic disease



No metastatic disease

Median survival:	1.3 years
1-year survival:	59.2%
2-year survival:	15.2%

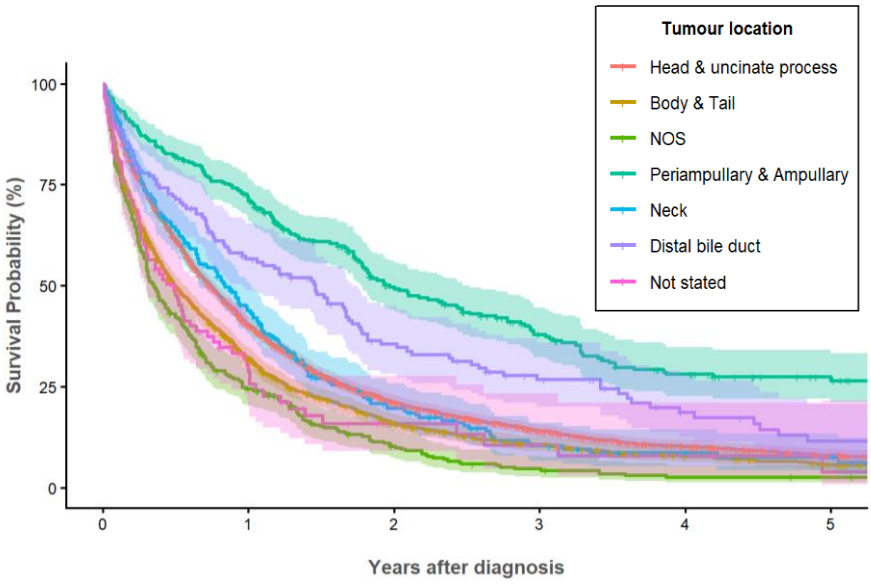
Metastatic disease

Median survival:	2.9 months
1-year survival:	17.6%
2-year survival:	0.5%

Survival by tumour location

The survival rate was highest for those with periampullary or ampullary cancers. The lowest survival was for patients with tumours located in the head or uncinate process of the pancreas (Figure 15).

Figure 15: Survival by tumour location

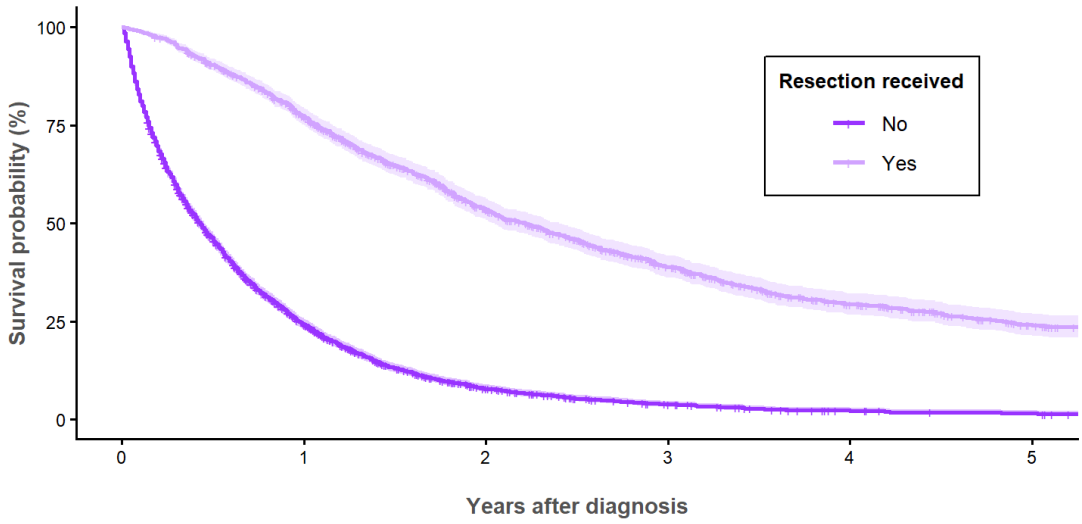


Median survival for:	
Head & uncinate process:	7.4 months
Neck:	8.4 months
Body & Tail:	5 months
Periampullary & ampullary:	2 years
Distal bile duct:	7.1 months
NOS (Not otherwise specified):	1.6 years

Survival by resection status

The survival rate was highest for those who had a resection (Figure 16).

Figure 16: Survival by resection status



No resection received		Resection received	
Median survival:	4 months	Median survival:	2.4 years
1-year survival:	24.1%	1-year survival:	77.1%
2-year survival:	1.5%	2-year survival:	23.9%

Oesophagogastric Module

Foreword

Prof Wendy Brown, Oesophagogastric Module Clinical Lead

Oesophageal and gastric cancers are uncommon but highly lethal diseases. Their symptoms develop insidiously, so most patients present late and diagnosis can be challenging. Treatment is complex, often requiring combinations of chemotherapy, radiotherapy, endoscopic interventions, and surgery. Because of this, patients need coordinated, multidisciplinary care to achieve the best possible outcomes.

This five-year report from the Victorian Upper Gastrointestinal Cancer Registry provides critical insights into how care is delivered across our State, and how this translates into survival. Benchmarking our outcomes enables us to celebrate successes, identify gaps, and drive improvements. Encouragingly, Victorian survival rates mirror international standards, reflecting strong adherence to optimal care pathways, effective use of adjuvant therapies, and world-class surgical complication rates.

However, several important opportunities for improvement emerge. Two-thirds of patients are diagnosed with Stage IV disease, highlighting the need for greater awareness of early symptoms and research into earlier detection strategies. Among those with advanced disease, too few are discussed at multidisciplinary team meetings or referred to palliative care, limiting opportunities to optimise quality of life. Timeliness of treatment also requires attention, with only 30% of patients commencing therapy within 60 days of diagnosis, despite national recommendations suggesting treatment should start within 42 days[1]. Supportive care is another critical gap: fewer than 60% of patients are referred to a dietitian, despite the profound impact of these cancers and their treatment on nutrition.

Surgical care is another key area for reflection. In 2024, oesophagectomies were performed at 30 centres across Victoria, but Registry data were contributed by only 21. International and local evidence shows that centralising oesophageal surgery into higher-volume centres improves outcomes by reducing variability, strengthening care pathways, and enabling rapid recognition of complications[2]. Victoria already has the framework to achieve this, with most patients able to access chemotherapy and radiotherapy locally, while travelling to a specialist surgical centre when needed. Linking centralised surgery with ongoing Registry participation would enable real-time performance monitoring, ensuring continuous improvement within a true learning healthcare system.

This report underscores both the progress already made and the opportunities ahead. By working together, clinicians, health services, consumers and policy makers - we have the chance to improve not only survival, but also the quality of care and experience for every Victorian facing these challenging cancers.

Prof Wendy Brown
MBBS (Hons), PhD, FRACS, FACS
Head, Oesophagogastric and Bariatric Unit, The Alfred
Head of Department of Surgery, Monash University, Alfred Campus
Program Director of Surgical Services, Alfred Health

Demographics and Disease

70 years
median age at diagnosis

68%
were male

55%
were born overseas

88%
English as preferred language

65%
live in metropolitan areas

- **68%** of patients were male.
- While **55%** of patients were born overseas, **88%** identified English as their preferred language.
- The majority of patients were diagnosed with cancer at the gastro-oesophageal junction (**41%**), followed by the stomach (gastric, **33%**) and oesophagus (**25%**).
- The majority of patients (**97%**) had a tissue biopsy prior to treatment.

Figure 17: Site of tumour

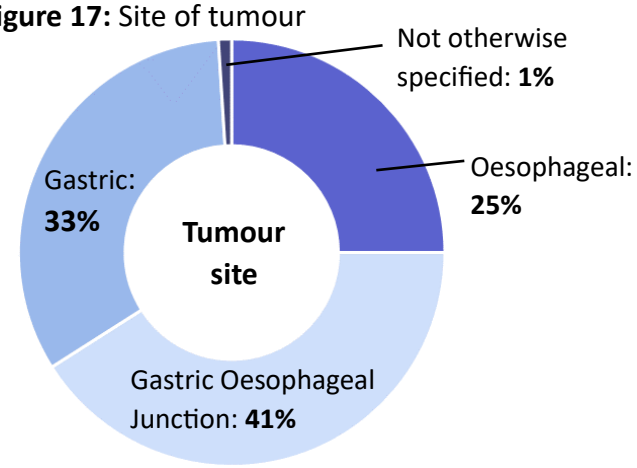
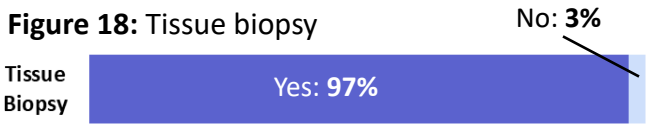
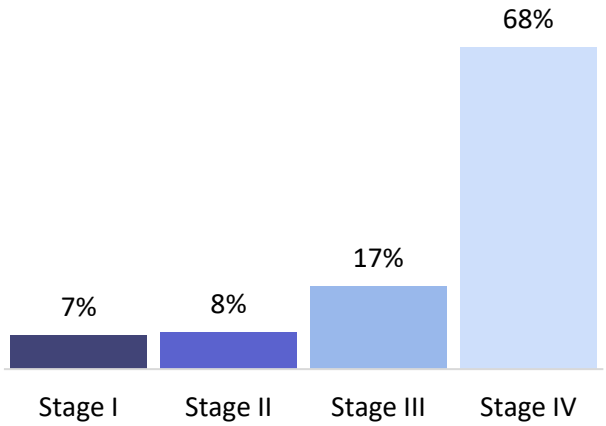


Figure 18: Tissue biopsy



- Among the patients with stage documented, 68% were diagnosed with Stage IV cancer.
- Approximately 15% of patients were diagnosed with early-stage cancer (Stage I and II).

Figure 19: Stage at diagnosis



Most patients receiving treatment lived close to their treating hospital, with 85.5% of patients receiving neoadjuvant treatment and 88% of patients receiving adjuvant chemotherapy travelling less than one hour.

The majority of patients receiving radiotherapy travelled less than one hour to their treating hospital, including 78.5% of those receiving neoadjuvant radiotherapy and all patients receiving adjuvant radiotherapy.

78% patients travelled less than one hour to their surgical resection site, while 16% travelled between one and three hours.

Patterns of Care

36%
had a surgical resection

53%
had chemotherapy

42%
had radiotherapy

28%
had no treatment

57.1% of patients received a PET scan.

38.4% of patients were referred to palliative care.

30.3% of patients received treatment within 60 days of referral.

59.1% were referred to a dietician.

89% of patients were discussed at a multidisciplinary meeting (MDM). All patients with Stage I and II cancer were discussed at an MDM while 80% of patients with Stage IV were discussed (Figure 22).

Figure 20: Type of resection in oesophageal cancer

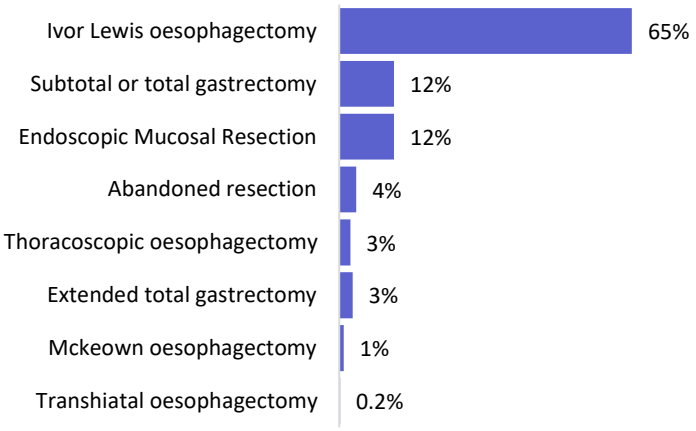


Figure 21: Type of resection in gastric cancer

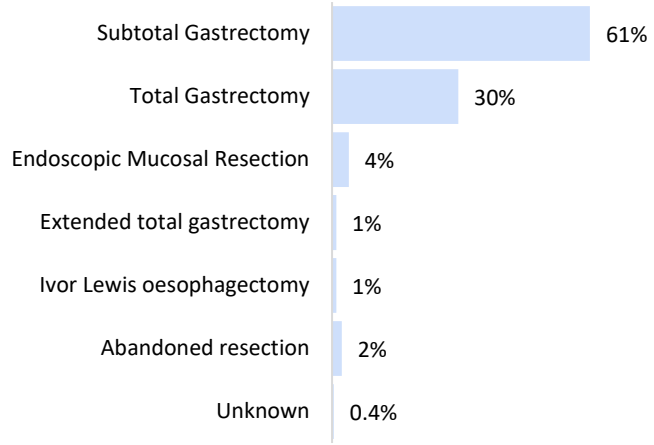
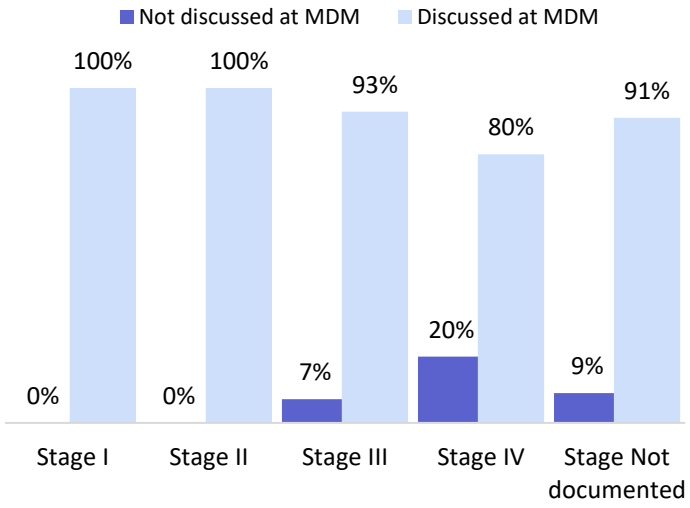


Figure 22: Discussion at a multidisciplinary meeting by stage



16.7% of patients had neoadjuvant chemotherapy prior to surgery.

8.1% of patients had adjuvant chemotherapy after surgery.

7.3% of patients had neoadjuvant radiotherapy before surgery.

16.7% of patients had adjuvant radiotherapy after surgery.

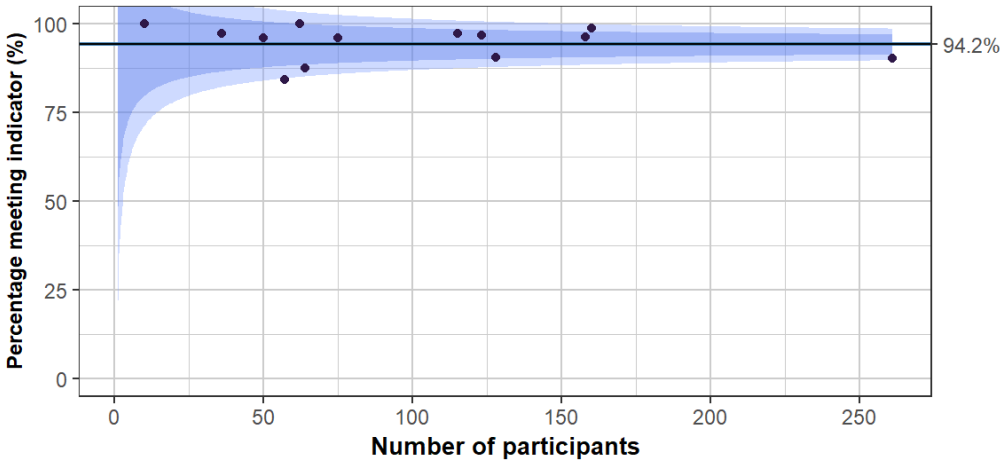
Key Quality Indicators for Oesophagogastric Cancers

The UGICR collects and reports on data relating to 22 clinical quality indicators (CQIs) for the oesophagogastric module. These CQIs have been developed by an expert working group. They are risk adjusted and benchmarked against the UGICR cohort (see **Appendix 2** for full list of oesophagogastric CQIs). Four CQIs are illustrated below for descriptive purposes.

CQI: Proportion of patients who have a histological confirmation of diagnosis prior to any anti-tumour treatment.

The overall mean proportion of patients with histological confirmation of diagnosis prior to treatment was **94.2%**, with most health services having their performance within 95% of the overall mean (Figure 23).

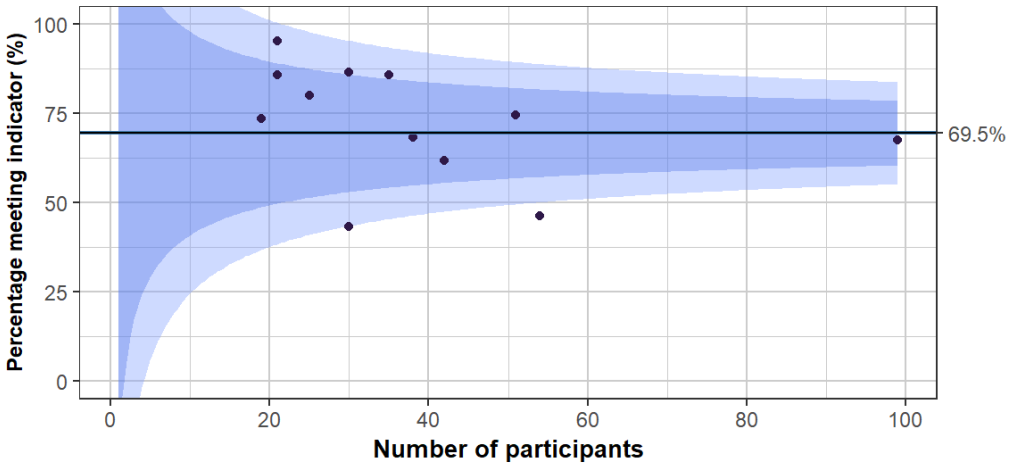
Figure 23: Patients with histological confirmation of diagnosis prior to treatment



CQI: Patients with distant metastatic disease who were seen by palliative care.

The overall mean proportion of patients with distant metastatic disease who were seen by palliative care was **69.5%**, with most health services having their performance within 95% of the overall mean (Figure 24).

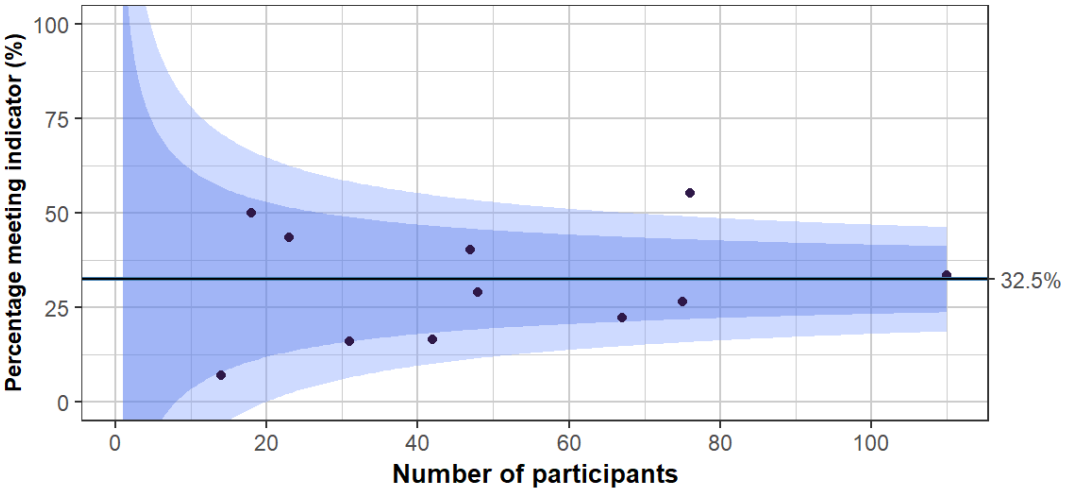
Figure 24: Patients with distant metastatic disease who were seen by palliative care



CQI: Patients who had intraoperative or post-operative complications.

The overall mean proportion of patients who had intraoperative or post-operative complications was **32.5%**, with most health services having their performance within 95% of the overall mean (Figure 25).

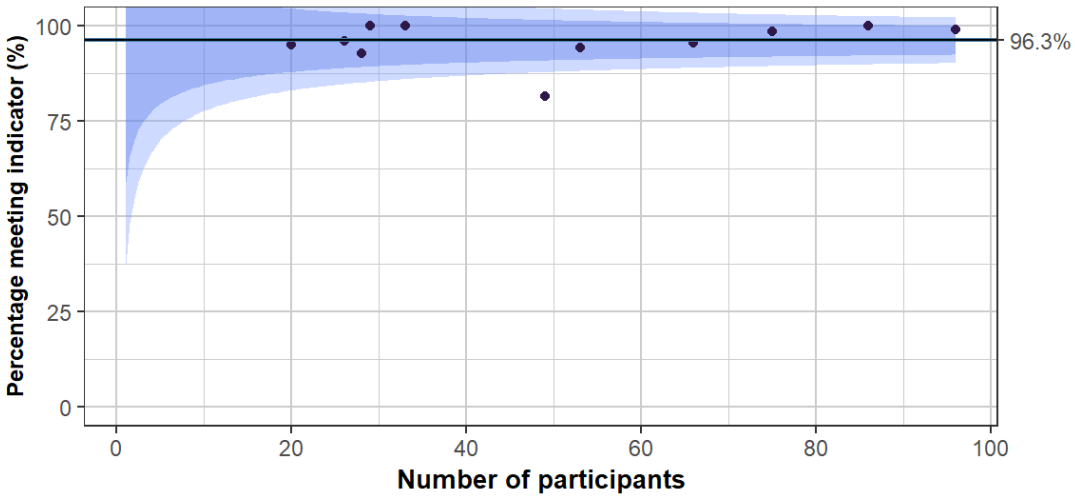
Figure 25: Patients who had intraoperative or post-operative complications



CQI: Patients with non-metastatic oesophageal or junctional tumours who had pre-treatment PET/CT scan.

The overall mean proportion of patients who had a PET or CT scan among those with non-metastatic oesophageal or junctional tumours was **96.3%**, with most health services having their performance within 95% of the overall mean (Figure 26).

Figure 26: Patients who had non-metastatic oesophageal or junctional tumours who had pre-treatment PET/CT scan

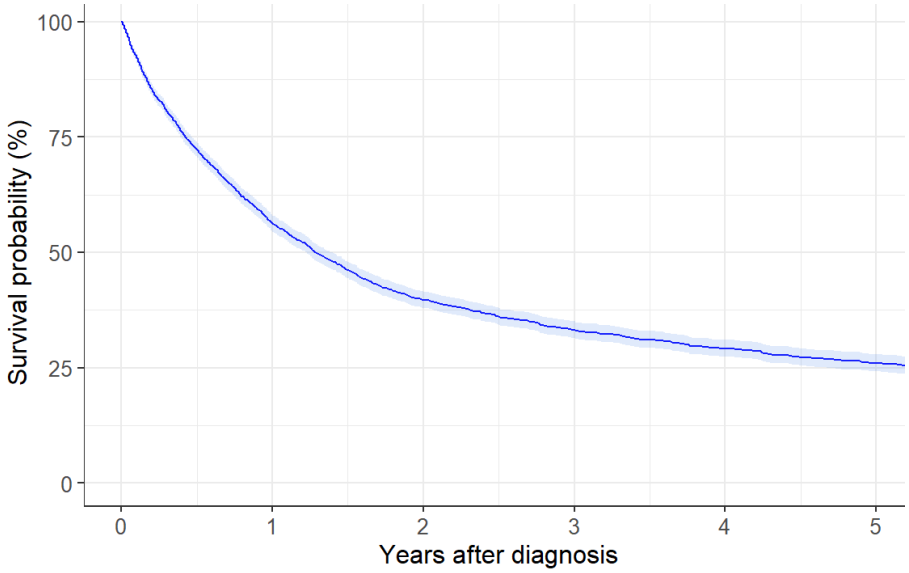


Survival of Patients with Oesophagogastric Cancers

Overall survival

The median survival for patients with oesophagogastric cancer was 1.3 years (Figure 27).

Figure 27: Overall survival for oesophagogastric cancer patients

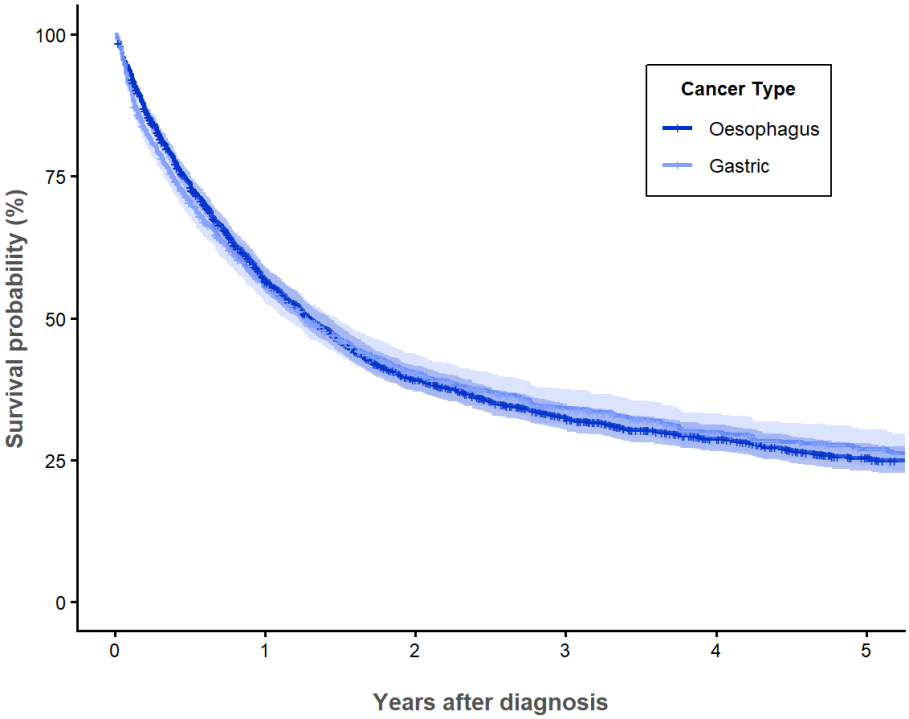


Median survival:	1.3 years
1-year survival:	56%
2-year survival:	40%
5-year survival:	26%

Survival by cancer type

The median survival, 1-year and 5-year survival were similar for patients with oesophageal or gastric cancer (Figure 28).

Figure 28: Overall survival for by cancer type



Oesophageal cancer

Median survival:	1.3 years
1-year survival:	57%
5-year survival:	26%

Gastric cancer

Median survival:	1.3 years
1-year survival:	56%
5-year survival:	27%

Primary Liver Module

Foreword

Professor Stuart Roberts, Primary Liver Module Clinical Lead

The Primary Liver module was established in June 2022 by Prof John Zalcberg (academic lead) and Stuart Roberts (clinical lead)[3]. Clinical governance of The Primary Liver Module is via a multi-disciplinary expert working group that includes representatives of all key stakeholder groups involved in the management of this condition including diagnostic and interventional radiologists, hepatologists, hepatobiliary surgeons, radiation and medical oncologists, palliative care physicians, liver cancer nurses, and consumers. The Primary Liver module is a unique module within the UGICR as it is a national clinical quality registry (CQR) that involves at present eighteen sites with ethics and governance approval across Victoria (n=8), NSW (4), Queensland (4), South Australia (1), Western Australia (1) and the Northern Territory (1). Currently, fourteen sites are active in collecting and entering in data prospectively on patients with primary liver cancer and as of the 29th July 2025, a total of 1255 patients have been entered into the screening database by around 30 clinicians across the various sites, with initial data collection commenced on just over 700 patients.

In the initial review of the prospective database for the Annual report involving the first 424 patients included in the database over three years from 2021-2023, the demographic characteristics were typical of an Australian cohort with primary liver cancer being an older age group with median age 69 years, mostly male, around 40% born overseas and two-thirds living in metropolitan areas. Notably, the vast majority (80%) had liver cirrhosis with the primary underlying aetiologies being alcohol, viral hepatitis B and C, and metabolic dysfunction-associated fatty liver disease. Importantly, around 60% were diagnosed across sites at an early or very early stage of disease with just over 40% being offered some form of curative therapy initially following diagnosis. The first benchmarking of sites is expected to be performed in the first quarter of 2026 that will target in the first instance surveillance and diagnosis, as well as utilisation of a multi-disciplinary team at liver centres.

Alongside the prospective primary liver cancer module has been the development of a retrospective primary liver cancer database across 10 sites in Victoria and NSW whose primary aim has been to evaluate the factors associated with overall survival in patients with early-stage primary liver cancer. Several studies to date have already been published from the retrospective cohort that describe variations in treatment patterns and survival outcomes in early-stage HCC patients according to treatments received and liver centre type[4-6]. Plans are underway to expand the data collected and to include data from overseas via our international collaborators in Canada, Japan and the United Kingdom.

Prof Stuart Roberts
MBBS, MD, MPH, FRACP, FAASLD
Professor of Hepatology
Alfred Hospital

Demographics and Disease

69 years
median age at diagnosis

80%
were male

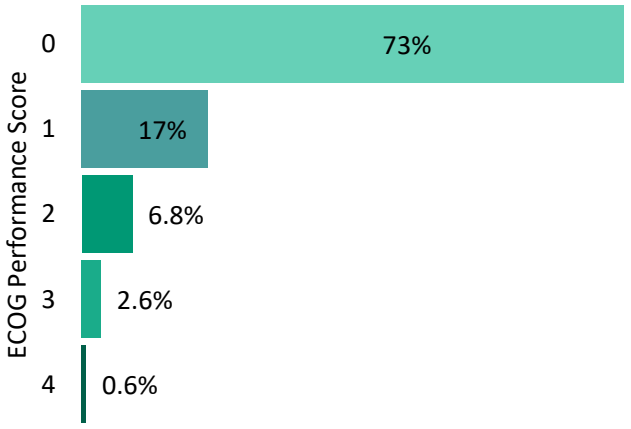
43%
were born overseas

82%
English as preferred language

62%
live in metropolitan areas

- Overall, **37%** of patients were Caucasian and **11%** were of Asian ethnicity.
- Liver cancer aetiology showed that **22%** of patients had cancer related to alcohol, **17%** to fatty liver disease, **16%** to hepatitis C, and **14.2%** to alcohol and viral hepatitis (Table 5).
- **73%** of patients had a good ECOG performance status (score 0–1), while only 10% had a poor performance status (score ≥2), Figure 29.

Figure 29: ECOG status at diagnosis



- **26%** has a tissue sample taken prior to or at the same time as HCC anti-tumour treatment.

Figure 30: Stage at diagnosis

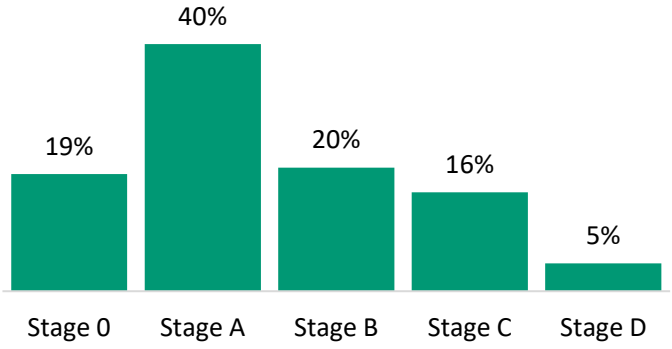


Table 5: Liver cancer aetiology

Alcohol	22%
Fatty Liver Disease (NAFLD/MAFLD)	17%
Hepatitis C	16%
Alcohol + viral Hepatitis (B or C)	14.2%
Hepatitis B	12%
Alcohol + Fatty Liver Disease	5.9%
Other	12.9%

NAFLD: Non-alcoholic fatty liver disease, MAFLD: Metabolic associated fatty liver disease

Among those with alcohol-related liver disease, **45%** had a history of heavy alcohol use and **41%** were current heavy users.

38% of patients were diagnosed with diabetes (Type 1 or Type 2).

34% of patients were current smokers, **37%** ex-smokers and **28%** never smokers.

A majority of patients (**80%**) had underlying liver cirrhosis.

40% had portal hypertension at the time of diagnosis.

12% had a high Charlson Comorbidity Index (CCI ≥3), **60%** had mild comorbidities (CCI 1–2), and **27%** had no recorded comorbidities.

- Staging was through the Barcelona Clinic Liver Cancer (BCLC) method. The majority of patients were staged as BCLC A (**40%**), followed by BCLC B (**20%**), BCLC 0 (**19%**), BCLC C (**16%**), and BCLC D (**4.7%**), Figure 30.

Patterns of Care

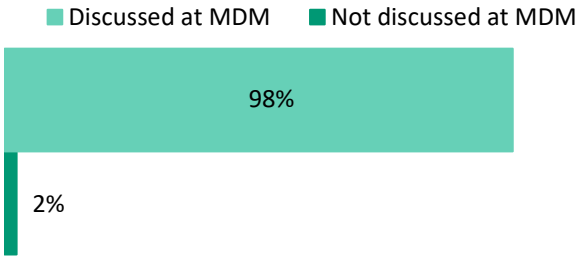
16% had a surgical resection

27% had chemotherapy

4.2% had radiotherapy

3.3% had no treatment

Figure 31: Discussion at a multidisciplinary meeting



52% of patients had treatment within 60 days of referral.

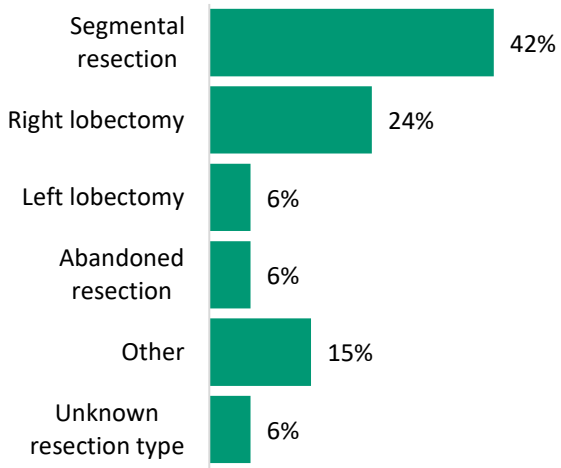
90% of patients overall had a referral to palliative care.

2.1% of patients had a liver transplant.

19% of patients had a liver ablation.

- **27%** of patients received chemotherapy and **4.2%** received radiotherapy.
- Only **3.3%** had no treatment.
- A majority of patients with liver cancer (**98%**) were discussed at a multidisciplinary meeting (Figure 31).
- **36%** of patients had surgery.
- Among patients that had a resection, the most common type was segmental resection (**42%**), Figure 32.

Figure 32: Type of surgical resection



Key Quality Indicators for Liver Cancer

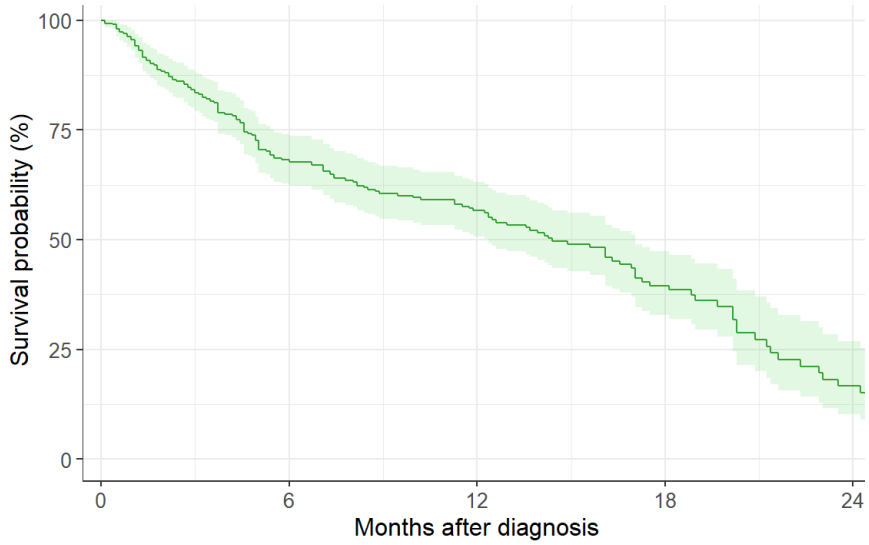
The primary liver cancer CQR aims to identify variation in care and explore reasons for it to impel change, and to promote evidence-based practice by assessing compliance with established best practice, as defined by a core set of CQI's established for primary liver cancer via a modified Delphi process. The core set of 23 CQI's that cover screening, diagnosis, staging, and management were chosen based on the criteria of being feasible and appropriate to measure by health services in Australia managing primary liver cancer patients (see **Appendix 3** for full list of primary liver cancer QIs). Monitoring adherence to these best practice CQIs at national level via the primary liver cancer registry may lead to system-level improvement in quality of care and, ultimately, improvement in patient outcomes, including survival. A comprehensive quality indicator report is currently in development and is expected to be available by in early 2026.

Survival of Patients with Liver Cancer

Overall survival

The one-year survival for patients with liver cancer was 57% (Figure 33).

Figure 33: Overall survival for liver cancer patients

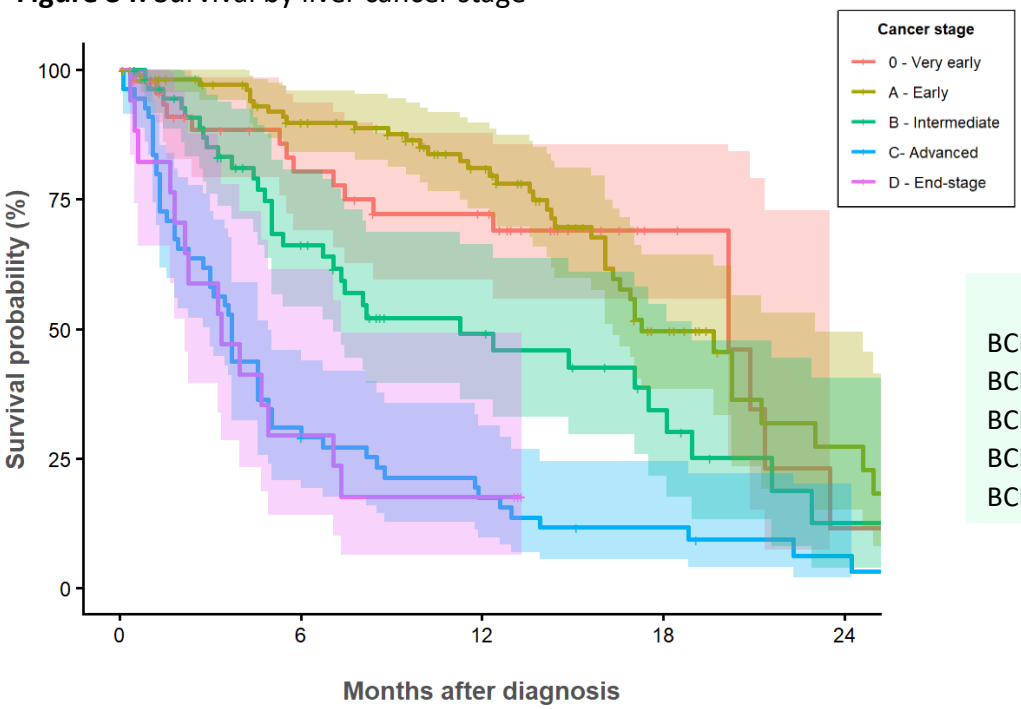


1-year survival:	57%

Survival by clinical stage

Survival outcomes varied by stage, with patients diagnosed at stages 0–A having higher one-year survival, and those with stages C and D experiencing lower survival rates (Figure 34).

Figure 34: Survival by liver cancer stage



1-year survival	
BCLC Stage 0:	72.2%
BCLC Stage A:	81.1%
BCLC Stage B:	49.1%
BCLC Stage C:	17.5%
BCLC Stage D:	17.6%

Liver – Pilot Retrospective Study

Overview

The liver retrospective study was conducted as a pilot to inform the development of the prospective liver registry. It included patients diagnosed with early stage hepatocellular carcinoma (HCC) between 1 January 2016 and 31 December 2020. Data were collected retrospectively from medical records across seven liver centres in Victoria and three centres in New South Wales.

Clinical data were collected from the time of HCC diagnosis (the index date) through to the end of follow-up (defined as the earliest of death, last medical record entry, or date of data extraction). A total of 967 patient records were extracted from relevant unit databases and electronic medical records. Further data collection was limited to patients with early-stage HCC and preserved liver function (Child-Pugh class A or B).

Results

80.4% male
19.6% female

84.0% had liver cirrhosis at diagnosis

52.5% had clinically significant portal hypertension

Table 6: Ethnicity

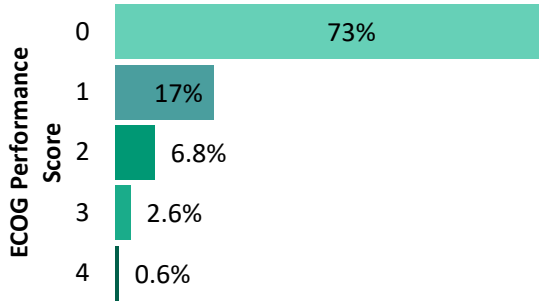
Caucasian	72.3%
Indigenous or Aboriginal Torres Strait Islander	2.4%
South East Asian	11.4%
North East Asian	5.0%
South Asian	2.9%
Middle Eastern	2.4%
Hispanic	1.3%
African	1.2%
Polynesian	1.2%

Table 7: Aetiology of liver disease

Alcohol + viral	28.0%
Hepatitis C Virus (HCV)	17.6%
Alcohol	15.1%
Non-alcoholic fatty liver disease (NAFLD)	11.9%
Alcohol + NAFLD	6.2%
Hepatitis B Virus (HBV)	6.2%
NAFLD + Viral	1.8%
HBV + HCV	1.2%
Other	6.5%

- The majority of patients diagnosed with liver cancer in this study were Caucasian (72.3%).
- Patients of South Asian (11.4%), North Asian (5.0%), and Southeast Asian (2.9%) backgrounds comprised the next largest groups.
- The most common underlying liver disease was a combination of alcohol-related liver disease with either Hepatitis B or C (28.0%), followed by Hepatitis C alone (17.6%) and alcohol-related liver disease alone (15.1%).
- Non-alcoholic fatty liver disease (NAFLD) accounted for 11.9% of cases.
- At diagnosis, most patients had a good ECOG performance status, with 81% recorded as ECOG 0 and 17% as ECOG 1. Only around 3% of patients had a poor ECOG performance status (score of 2 or higher).

Figure 35: ECOG performance score



A majority of patients (**84%**) had underlying liver cirrhosis.

The median pre-diagnosis Charlson Comorbidity Index score was **4.8**.

Biliary Module

Foreword

A/Prof Charles Pilgrim, Biliary Module Clinical Lead

As the clinical lead of the Biliary Module of the Upper Gastrointestinal Cancer Registry, it is with great pleasure that I introduce the initial data collected in the pilot phase of this module gathered between January 2019 and December 2023. This reports staging, treatment and outcome data of relevance to the rarest form of Upper GI cancer collected by the registry and represents the most recent component of the registry's efforts in improving care for patients with upper gastrointestinal cancers overall.

The pilot phase of the Biliary Module marks a significant milestone. Developed through close collaboration with clinical experts, data managers, and advisory groups, this module was designed to capture meaningful, real-world data on the diagnosis, treatment, and outcomes of patients with biliary tract cancers across multiple tumour subtypes. With 142 patients included in this initial phase, the data presented here provide an important early snapshot of care pathways and highlight areas for quality improvement.

As with all modules under the UGICR, our objective remains clear: to identify variation in care, measure adherence to evidence-based guidelines, and ultimately contribute to better outcomes for patients. Already, insights from the pilot, such as the low rate of disease-specific imaging prior to surgery or the proportion of patients commencing treatment within optimal timeframes have informed the next stage of development. Acknowledgement of wide variations in practice have led to further work at a national level to identify and agree on key outcomes and parameters on which to focus, with a modified Delphi process to finalise these quality indicators to follow.

Following this, with appropriate funding, the module will transition into full-scale prospective data collection, enabling us to report ongoing outcomes and support benchmarking across institutions. Importantly, the biliary module, like the others in the registry, is closely linked with a number of translational and implementation research projects. These are outlined later in this report and reflect the UGICR's commitment not only to data collection, but to data-driven action.

I extend my sincere thanks to the clinicians, patients, researchers, and data teams who have contributed to this important work. It is only through their continued involvement that we can ensure the UGICR remains a robust, relevant, and impactful tool for improving cancer care in Australia.

Charles Pilgrim
MBBS, FRACS, PhD, FACS
Upper GI Surgeon
Miltary and Trauma Surgeon, Royal Australian Army Medical Corps
Clinical Lead - SCANPatient Project

Pilot data

The biliary module has completed its pilot study and is currently undergoing a modified Delphi process to finalise the quality indicators. Following this, the database will be updated and prospective data collection will commence. For the pilot study, 142 participants were included. The results of this study are shown below.

Table 8: Biliary module patient characteristics

Participant characteristics	Number (%)
Age, years (mean ± SD*)	71.4 ± 12.6
Sex	
Female	72 (51%)
Male	70 (49%)
Tumour site	
Hilar	29 (20%
Intrahepatic	58 (41%)
Gallbladder	43 (30%)
Biliary (not otherwise specified)	11 (8%)
Unknown	1 (1%)
Resectability at diagnosis	
Resectable	28 (20%)
Unresectable	83 (58%)
Not documented	31 (22%)

**SD = Standard Deviation*

- The average age at diagnosis was **71.4** years.
- **51%** of patients were females.
- The most common tumour site was intrahepatic (**41%)** followed by gallbladder (**30%**) and hilar (**20%**).
- **63 (44%)** had anti-tumour treatment (excluding incidental gallbladder cancer diagnosis).
- Of these 63 patients, **36** had chemotherapy and/or radiotherapy, **17** completed resection and **6** had abandoned resection.
- **60 (42%)** of patients had no treatment.
- **15** patients had incidental gallbladder cancer diagnosis, of whom **4** underwent a re-resection.

85% of patients were discussed at a multidisciplinary meeting prior to receiving treatment.

80% of patients had a recorded CA19-9 level prior to surgery or treatment.

41% of patients had documented disease specific gold standard imaging prior to resection surgery.

90% of patients referred to (or seen by) a palliative care specialist.

10% of patients with two or more Emergency Department presentations in the last 30 days before death.

57% of patients had a time from referral to definitive treatment (surgical and/or other treatment) within 60 days.

- By subtype, 36% of hilar, 50% of intrahepatic patients, and 86% of gallbladder cancer patients commenced treatment within 60 days of referral.

Associated Studies

The UGICR has a number of associated studies across the three modules. Refer to Table 9 below for a summary of the current studies that are being undertaken by the UGICR team. For a list of completed projects, please see **Appendix 4**.

Table 9. Summary of UGICR associated studies in progress

Associated study & description	Status	Pancreas Module	OG module	Liver module
PROpatient: Symptom monitoring and centralised care coordination for patients with pancreatic and oesophagogastric cancer A VCA project grant was awarded in 2018 for a registry-based randomised control trial (RRCT) of symptom monitoring, using patient-reported outcomes, and care-coordination integrated into clinical practice to improve health-related quality of life in patients diagnosed with pancreatic and oesophagogastric cancers.	In progress	✓	✓	
PAN-EXPERT: Optimising Nutrition in Pancreatic Cancer - Examining PERT Implementation in Australia This study investigates the use of pancreatic enzyme replacement therapy (PERT) in patients with pancreatic cancer at highest risk of pancreatic enzyme insufficiency (PEI), particularly post-surgery. It also explores current management practices and opportunities to improve patient quality of life.	In progress	✓		
HER2 testing in advanced gastric cancer: understanding and reducing variation in current practice to improve patient survival This VCA funded project aims to characterise current practice and the quality of testing HER2 and explore processes to implement standard algorithms for assessing HER2 status in patients with advanced or recurrent gastric cancer in Victoria.	In progress		✓	
SCANPatient: Synoptic reporting of CT scans assessing cancer of the pancreas In this MRFF funded randomised controlled trial, researchers will test whether a structured radiology report can improve the accuracy of reporting of CT scans in pancreatic cancer to optimise care.	In progress	✓		
Survival outcomes of curative therapies in early-stage hepatocellular carcinoma A multicentre, noninterventional, retrospective study to describe and compare the impact of locoregional treatments compared with surgery on survival outcomes in patients with early-stage hepatocellular carcinoma.	In progress			✓
iCare – An interactive online portal to improve health and wellbeing for people living with complex cancers, and their informal carers: a Phase II randomised controlled trial An MRFF Partnership Grant study to test the feasibility and acceptability of iCare – a first-of-its-kind tailored, interactive web-based portal – to help deliver meaningful health impacts for people living with upper gastrointestinal cancers and their carers	In Progress	✓	✓	✓

Associated study & description	Status	Pancreas Module	OG module	Liver module
Real World HER2+ testing in advanced gastric/GEJ cancer in Australia This is a retrospective review of Australian pathology laboratories testing HER2+ in advanced gastric and gastroesophageal junction cancer.	In progress		✓	
Victorian Pancreatic Cancer Biobank This is an investigator-led study that involves individuals with a suspected diagnosis of pancreatic cancer or cholangiocarcinoma. This study involves banking surgical and fine needle aspirate (FNA) samples to provide a comprehensive resource for future research into pancreatobiliary cancer genetics and personalised therapy.	In progress	✓		

Acknowledgements and Funding

The UGICR acknowledges and pays respect to the Elders and Traditional Custodians of the lands, past, present, and emerging, on which we conduct our work and collaborate with our registry partners. We extend our gratitude to all patients and consumers who have contributed to the UGICR, as well as to each participating health service, their clinical staff, data collectors, and other personnel, whose collaboration has been essential to the success of the registry. We also thank the members of the UGICR Steering Committee for generously volunteering their time in support of the registry. Finally, we wish to acknowledge the contributions of former UGICR staff members, including Elysia Greenhill, Benjamin Brown, TJ Muhlen-Schulte, and Jennifer Holland, whose work has been integral to the development of the registry.

The UGICR received funding from the Australian Government. It is also supported by a range of pharmaceutical partners. Detailed funding information is available on request.

Future Directions

- Continue providing benchmarked quality indicator reports to participating hospitals to support care improvement for patients with upper GI cancers.
- Ongoing analysis of UGICR data (pancreatic, oesophagogastric, liver), with aggregated findings to be presented at national and international conferences.
- Support of multiple associated research projects and new projects beginning in 2025.
- Expand data collection for the Liver module to additional sites across NSW and other states and territories.
- Transition the Biliary module into the National Biliary Cancer Registry in partnership with AGITG and University of Sydney.
- Secure stable, long-term funding to ensure sustainability of the registry.
- Continue generating real-world evidence to support research and policy.
- Maintain and strengthen engagement with consumer representatives to meet community expectations for reporting outputs.

Publications and Presentations

Journal Publications

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2. Maharaj AD,* Holland JF,* Scarborough RO, Evans SM, Ioannou LJ, Brown WA, Croagh DG, Pilgrim CHC, Kench JG, Lipton LR, Leong T & Zalcberg, JR (2019). The Upper Gastrointestinal Cancer Registry (UGICR): a clinical quality registry to monitor and improve care in upper gastrointestinal cancers. BMJ Open, 9(9): e031434.
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21. Croagh D. Optimising Nutrition in Pancreatic Cancer: Examining PERT Implementation in Australia study. Epworth Research Month, Melbourne, Australia (2022).
22. Ioannou LJ. PROpatient: A registry-randomised control trial of patient-reported outcomes integrated into clinical practice. International Society for Quality of Life Research (ISOQOL) Measuring What Matters in Oncology Symposium, Virtual only (2023).
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10. Quinn M, Muhlen-Schulte T, Holland J & Brown WA, on behalf of the UGICR oesophagogastric working party. Upper Gastrointestinal Cancer Registry: Oesophagogastric cancer module pilot results. Australasian Gastro-Intestinal Trials Group (AGITG) Annual Scientific Meeting, Adelaide, Australia (2019).
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20. Bavor C. Registry-Based Patient-Reported Outcome Measures (PROMs) & Experience Measures (PREMs) for Pancreatic Cancer: A Pilot Study. Epworth Research Week, Melbourne, Australia (2021).
21. Khan N. A qualitative investigation of the supportive care experiences of people living with pancreatic and oesophagogastric cancer. International Society for Quality of Life Research (ISOQOL) Annual Conference, Virtual only (2021).
22. Holland J. Registry-based patient-reported outcome measures (PROMs) and experience measures (PREMs) for pancreatic cancer: A pilot Study. Using PROMs Down Under, Sydney, Australia (2021).
23. Khan N. Characteristics of patients diagnosed with pancreatic cancer who access palliative care: An observational study. Multinational Association of Supportive Care in Cancer (MASCC) Annual Meeting, Toronto, Canada (2022).
24. Roberts S, et al. Monitoring quality of care in hepatocellular carcinoma: A modified Delphi consensus. American Association for the Study of Liver Diseases (AASLD)- The Liver Meeting, Washington, USA (2022).
25. Lam E, et al. Expansion of a multimodular Clinical Quality Registry: Establishing the Upper Gastrointestinal Cancer Registry (UGICR) Liver Cancer Module. Epworth Research Month, Melbourne Australia (2022).
26. Roberts S, et al. Monitoring quality of care in hepatocellular carcinoma: A modified Delphi consensus. Alfred Health Week Scientific Abstract Competition, Melbourne, Australia (2022): MPCCC PRIZE FOR BEST ABSTRACT IN CANCER RESEARCH.
27. D'souza B, et al. HER2 testing in advanced gastric cancer – understanding and reducing variation in current practice to improve equity in patient outcomes. Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting, Melbourne, Australia (2023).
28. D'souza B, et al. HER2 testing in advanced gastric cancer – understanding and reducing variation in current practice to improve equity in patient outcomes. Australasian Gastro-intestinal Trials Group Annual (AGITG) Scientific Meeting, Brisbane, Australia (2023).

Conference Poster Presentations continued

29. D'souza B, et al. HER2 testing in advanced gastric cancer – understanding and reducing variation in current practice to improve equity in patient outcomes. Cabrini Research Forum, Melbourne, Australia (2023).
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31. D'souza B, et al. HER2 testing in advanced gastric cancer – understanding and reducing variation in current practice to improve equity in patient outcomes. Australian Clinical Registry Annual Scientific Meeting, Melbourne, Australia (2023).
32. D'souza B, et al. PROpatient: a registry-based randomised controlled trial of symptom monitoring and care coordination to improve quality of life for patients with upper gastrointestinal cancer. Australian Clinical Registry Annual Scientific Meeting, Melbourne, Australia (2023).
33. Lam, E, et al. Establishing the clinical quality registry upper gastrointestinal cancer registry liver module. Cabrini Research Forum, Melbourne, Australia (2023).
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35. Recasens A. Can a new standard of radiology reporting help in the diagnosis of pancreatic cancer? Cabrini Research Forum, Melbourne, Australia (2023).
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Appendix

Appendix 1: Pancreatic Module Quality Indicators

Number	Description
1a	Proportion of all non-metastatic patients with pancreatic cancer who underwent a pancreatic protocol CT or MRI scan to confirm diagnosis and/or staging.
1b	Proportion of all non-metastatic patients with pancreatic cancer who underwent a pancreatic protocol CT scan to confirm diagnosis and/or staging.
2	Proportion of all patients who underwent any treatment with chemotherapy or radiotherapy (this includes neoadjuvant therapy) with attempted tissue biopsy to treatment.
3	Proportion of all patients who underwent surgery or other treatment with a documented CA19-9 level before treatment.
4a	Proportion of patients with documented operability of tumour as defined operable/resectable, borderline resectable, locally advanced (unresectable) or metastatic (unresectable).
4b	Proportion of patients with documented operability of tumour as defined operable/resectable, borderline resectable or locally advanced (unresectable).
5a	Proportion of patients with performance status documented as measured by ECOG prior to any treatment/at diagnosis.
5b	Proportion of patients with performance status documented as measured by ECOG or ASA prior to any treatment/at diagnosis.
6a	Disease management for all patients discussed at a multidisciplinary team meeting (MDM) prior to treatment.
6b	Disease management for all non-metastatic patients discussed at a MDM (multidisciplinary team meeting) prior to treatment.
7a	Proportion of patients who underwent neoadjuvant treatment restaged with the following imaging: MRI, PPCT or PET.
7b	Proportion of non-metastatic patients who underwent neoadjuvant treatment restaged with the following imaging: MRI, PPCT or PET.
8	Proportion of patients with documented definitive treatment (surgical and/or other treatment) within 60 days.
9a	Proportion of patients with unresectable disease who saw a medical or radiation oncologist or a reason documented for not doing so.
9b	Proportion of patients with unresectable disease who saw a medical or radiation oncologist.
10	Proportion of patients participating in a clinical trial.
11a	Proportion of patients with locally advanced disease administered chemotherapy ± chemo-radiation, or a reason documented for not undergoing treatment.
11b	Proportion of patients with locally advanced disease administered chemotherapy ± chemo-radiation.
12	For patients who do not undergo surgery have a reason documented.
13a	Proportion of patients with borderline resectable disease administered neoadjuvant treatment or a reason documented for not undergoing treatment.
13b	Proportion of patients with borderline resectable disease administered neoadjuvant treatment.
14a	Proportion of patients administered adjuvant chemotherapy following surgery.
14b	Proportion of patients administered adjuvant chemotherapy following surgery.
15	Proportion of patients who died within 30 days of chemotherapy.
16	Proportion of patients with metastatic disease referred to or seen by palliative care.
17	Proportion of patients who spent ≥14 days in acute hospital in the last 30 days of life.
18	Proportion of patients with ≥2 emergency department presentations in the last 30-days before death.

Number	Description
19	Proportion of patients with a RCPA or equivalent synoptic reporting used to document findings for patients undergoing surgical resection.
20	Proportion of patients with R1 resections (positive < 1mm margin) regardless whether they have a synoptic report or not.
21	Proportion of patients with ≥10 lymph nodes pathologically examined (or measure proportion who have less than 10 lymph nodes examined).
22	Proportion of patients who required a re-operation following surgical resection.
23a	Patients that died within 30 days of surgical resection.
23b	Patients that died within 90 days of surgical resection.

Appendix 2: Oesophagogastric Module Quality Indicators

Number	Description
1	Proportion of patients who have a histological confirmation of diagnosis prior to any anti-tumour treatment.
2a	Proportion of patients discussed at a multi-disciplinary team meeting by diagnosing hospital
2b	Proportion of patients receiving treatment who were discussed at a multi-disciplinary team meeting.
2c	Proportion of patients receiving no treatment who were discussed at a multi-disciplinary team meeting prior to treatment.
3a	Time (days) between multidisciplinary team meeting (MDM) presentation and first treatment date for Non-Metastatic patients.
3b	Time (days) between MDM presentation and first treatment date for Metastatic Patients.
4a	Proportion of patients with non-metastatic disease who died within 30 days of a chemotherapy dose.
4b	Proportion of patients with distant metastatic disease who died within 30 days of a chemotherapy dose.
7a	Proportion of patients who had intra-operative or post-operative complications.
8a	Proportion of patients with distant metastatic cancer who were seen by a palliative care physician or palliative care.
8b	Proportion of patients with metastatic cancer (include distant & regional lymph nodes) who were seen by a palliative care physician or palliative care.
9	Proportion of patients with metastatic cancer who were seen by a medical oncologist or radiation oncologist.
12a	Proportion of patients with gastric or junctional adenocarcinoma tumours who had a pre-treatment staging laparoscopy before resection.
12b	Proportion of patients with gastric tumours who had a pre-treatment staging laparoscopy before resection.
12c	Proportion of patients with gastric or junctional tumours who had a pre-treatment staging laparoscopy before resection.
13	Proportion of patients with non-metastatic oesophageal or junctional tumours who had a pre-treatment PET/CT scan.
14	Proportion of patients with planned surgery who had neo-adjuvant therapy and were re-staged afterwards using a CT (all tumour types) or PET scan (oesophageal or junctional cases).
15a	Proportion of cases where relevant surgical margin(s) are recorded as positive (≥1 mm) on the pathology report for those patients who have had surgical resection of the primary tumour.
15b	Proportion of cases where proximal or distal surgical margin(s) are recorded as positive (≥1 mm) on the pathology report for those patients who have had surgical resection of the primary tumour.

Number	Description
15c	Proportion of cases where circumferential surgical margin(s) are recorded as positive (≥1 mm) on the pathology report for those patients who have had surgical resection of the primary tumour.
15d	Proportion of cases where longitudinal surgical margin(s) are recorded as positive (≥1 mm) on the pathology report for those patients who have had surgical resection of the primary tumour.
16	Proportion of patients who have had a resection (as per item 15), the number of nodes examined should be maximised.

Appendix 3: Liver Module Quality Indicators

Number	Description
Diagnosis and Staging	
1.1	**Presentation, initial investigations and referral**
1.1.3	Specialist investigations to achieve a diagnosis completed within 4 weeks of referral.
1.1.4	Documented evaluation at baseline of underlying liver disease aetiology, presence/absence of cirrhosis, AFP level, extent of liver dysfunction (e.g., Child-Pugh Score or MELD and presence or absence of portal hypertension) and comorbidities (that impact management).
1.2	**Surveillance**
1.2.1	Documented regular surveillance with ultrasound and/or appropriate alternative liver imaging performed within 6-12 months before the first detection of HCC in known cirrhotic and at-risk patients managed though a specialist centre.
1.3	**Imaging Modalities and Pathology**
1.3.1	Diagnosis of HCC confirmed either by established imaging criteria (e.g., LI-RADS using multiphase CT or MRI or CEUS) or histologically.
1.3.2	Documented diagnosis in non-cirrhotic patients (not known to be at increased risk of HCC) is confirmed by histopathology.
1.5	**Staging**
1.5.1a	Tumour stage is clearly defined and documented using the BCLC staging system (Stage 0, Stage A-C, Stage D).
1.5.1b	All cirrhotic patients are stratified according to Child-Pugh score +/ or Model for End-Stage Liver Disease (MELD)and Barcelona Clinic Liver Cancer (BCLC) staging system.
1.5.2	Documented staging parameters include radiological imaging (tumour size, number and location of lesions, metastases and vascular invasion), Eastern Cooperative Oncology Group (ECOG) performance status and cirrhosis status and assessment of liver function (e.g., Child–Pugh score or MELD).
1.6	**Multidisciplinary Care**
1.6.1	Diagnosis, staging and treatment planning of a patient with suspected or proven HCC is managed by a multidisciplinary team.
Treatment and Management	
2.1	**Antiviral Therapy**
2.1.1	Patients with HCC (with or without cirrhosis) and viral hepatitis B or C should receive antiviral therapy.
2.2	**Localised Therapy**
2.2.1	Patients with early-stage HCC should receive therapy with curative intent.

Number	Description
2.2.2	Liver resection offered as first line therapy in patients with preserved liver function, sufficient liver remnant, and absence of significant portal hypertension (or a valid reason for not undergoing treatment).
2.3	**Liver Transplantation**
2.3.1	Documented discussion of liver transplantation in patients within overall transplant criteria who are not suitable for curative hepatic resection or ablative therapy.
2.3.2	Patients with HCC on the waiting list for liver transplantation should be monitored surveilled for HCC progression.
2.4	**Locoregional Therapy**
2.4.2	TACE or TARE or other therapies with intent to delay progression and prolong survival is offered to patients with BCLC-B stage HCC not suitable for curative treatment.
2.4.3	Documented response to HCC-directed treatment with contrast-enhanced CT or MRI every 3-6 months.
2.5	**Systemic Therapy**
2.5.1a	Documented that systemic therapy was offered to suitable patients with advanced HCC not amenable to curative or locoregional therapies with intent to prolong survival.
2.5.2	Currently approved first-line systemic therapy agents was offered to eligible patients with HCC.
2.6	**Supportive Care**
2.6.1	Patients with BCLC D are offered symptom management in conjunction with supportive care services.
2.6.3	Patients referred to palliative care in advanced disease.

Appendix 4: Completed UGICR projects

Associated study & description	Status	Pancreas Module	OG module	Liver module
PCR4QI: Pancreatic Cancer Registry for Quality Improvement An NHMRC project grant (2016) was awarded to Professor Sue Evans for Optimising care for patients diagnosed with pancreatic cancer: a prospective cohort study. This 5-year project uses UGICR pancreatic cancer data and expands the module into six NSW Local Health Districts.	Complete	✓		
Pancreatic Cancer Image Biobank This AVNER Pancreatic Cancer Foundation–funded project aims to compare European, North American, and Australian perspectives on the resectability of non-metastatic pancreatic cancer. Using data from the UUGICR, the project is establishing a secure image biobank containing diagnostic CT scans from 100 patients. These scans were reviewed by an international panel of surgeons and radiologists with expertise in pancreatic cancer, allowing comparison of how experts from different specialties, institutions, and countries assessed technical resectability.	Complete	✓		
Registry Derived (RD) Stage for pancreatic, stomach, liver, uterine and ovarian cancer project This study developed Business Rules to enable population-based registries to assign a stage at diagnosis for five cancer types. The RD Stage was subsequently validated for pancreatic and uterine cancers using data from population-based cancer registries across jurisdictions.	Complete	✓		

Associated study & description	Status	Pancreas Module	OG module	Liver module
Gastrointestinal cancer treatment and survival in culturally and linguistically diverse patients: Exploring health disparities in an Australian population. This study characterised the effect of cultural and linguistic diversity on health outcomes in a cohort of gastrointestinal cancer patients, aiming to inform strategies to improve outcomes for these patients.	Complete	✓	✓	
Integrating pancreatic cancer PROMs and PREMs into a clinical quality registry: Exploring the patient and clinician perspective The collection of electronic patient-reported outcome and experience measures (PROMs & PREMs) from patients with pancreatic cancer is being piloted. The funding received from the Monash Partners Comprehensive Cancer Centre will help shape the routine collection of PROMs and PREMs in the future.	Complete	✓		
Synoptic radiology reporting in pancreatic cancer pilot (with SMICS/NEMICS) This pilot study involves testing a new synoptic radiology reporting template for abdominal CT scans in suspected pancreatic cancer. Phase 1 will be conducted at two health services, while Phase 2 will assess inter- and intra-observer variability in synoptic reporting among multiple radiologists.	Complete	✓		
SYMPTOM-UGI: Pathways to diagnosis of upper gastrointestinal cancers A collaborative project led by Professor Jon Emery from the University of Melbourne, looking at patient pathways from onset of symptoms to cancer diagnosis. Potential participants for this project will be identified through the UGICR.	Complete	✓	✓	
National Pancreatic Cancer Roadmap Mapping of pancreatic cancer treatment and care against the optimal care pathway for people with pancreatic cancer (Cancer Australia). The UGICR was commissioned by Cancer Australia to map treatment and care against the Optimal Care Pathway. The report delivered contributed to the development of the National Pancreatic Cancer Roadmap.	Complete	✓		

UPPER GI CANCER REGISTRY

MONASH University

Five Year Report

Upper Gastrointestinal Cancer Registry