The Management of Hepatobiliary Cancer
Pathway of Care

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1.0 Pathway Overview

**SYMPTOMATIC PATIENT**

**PRIMARY CARE**

- High Index of Suspicion of Cancer
  - Jaundice (not related to drugs, alcohol or recent foreign travel)
  - Unexplained upper abdominal pain and weight loss
  - OGD negative abdominal pain
  - Steatorrhoea
  - Abnormal imaging

Refer urgently to local UGI team

GP to organise FBC, LFTs, aFP, Ca 19-9 and abdominal U/S en-route (these should NOT delay the urgent appointment)

**SECONDARY CARE**

- Local Management
  - Inoperable tumours – obvious widespread disease
  - Lymphomatous masses for pancreatic Bx
  - Inoperable hilar cholangiocarcinomas (Specialist MDT to be informed about these patients even if not referred)

Refer to Specialist Team:
  - Locally confined tumours
  - Obstructive jaundice, suspicion of Ca but imaging negative
  - Neuro-endocrine tumours
  - Para-duodenal tumours
  - Lower end bile duct tumours
  - Operable hilar cholangiocarcinomas
  - Duodenal adenomas

**TERTIARY CARE**

- Urgent HPB/Liver Clinic
  - Further tests such as EUS+/− MRI if necessary

- INOPERABLE Tumours
  - Refer back to local teams

- OPERABLE Tumours

**SURGERY**

**Specialist Palliative Care**
2.0 Introduction

In 2006, describing a model of care for patients with suspected/proven pancreatic cancer in Kent and Medway, the pancreatic sub-group of the Upper GI Tumour Site Specific Group (TSSG) endeavoured to reconcile the following views:

- Calman-Hine – Patients to be treated as closely to home as possible
- Improving Outcomes in Upper Gastro-intestinal Cancers – Patients to be treated by specialist teams
- Pancreatic cancer surgery to be performed in specialist centres
- Kent and Medway Upper GI TSSG – Local expertise should be capitalised upon
- Referral pathways that are known to work effectively should not be dismantled unless proposed new pathways are shown to be at least as effective if not better

3.0 Process and Terminology

3.1 Tumours

- Cancer of the pancreas
- Cancers affecting the bile ducts e.g.:
  - Cholangiocarcinoma
  - Metastases from other sites
  - Gall bladder cancer
- Hepatocellular carcinoma

3.2 Local referral guidelines and process

General practitioners are encouraged to refer patients with new jaundice or an abdominal mass as a matter of urgency.

Patients with suspected pancreatic/biliary cancer should be referred under the 2-week rule.

Patients with probable obstructive jaundice should be referred to a gastroenterologist in the first instance or transferred to their care to concentrate expertise and expedite investigation. Where possible patients should be managed in an ambulatory care setting (refer to local protocols)

The following symptoms should sound alarm bells with General Practitioners:
- Jaundice
- Weight loss
- Abdominal mass
- OGD negative abdominal pain
- Steatorrhoea
- Unexplained intractable low thoracic back pain

General Practitioners should be encouraged to organise the following investigations “en-route”:
- FBC
- LFTs
- U&Es
- Ca19-9 & AFP
- Upper abdominal Ultrasound (this should not delay urgent appointment with the specialist)

Radiologists are asked to comment on ultrasound assessment of:
- bile duct diameter & presence of intrahepatic duct dilatation
- pancreatico-biliary area for size and level of any observed mass
3.3 Imaging Guidelines

Full KMCC imaging guidelines are located on the KMCC website on the following link:
http://kmcc.nhs.uk/tumour-sites/sub-groups-or-cross-cutting-groups/diagnostics-group/

3.4 Pathology

All KMCC reporting pathologists follow The Royal College of Pathologists Histopathology Reporting on Cancers guidelines – a copy of which is available through the KMCC website:
http://kmcc.nhs.uk/tumour-sites/sub-groups-or-cross-cutting-groups/pathology-group/

3.5 Local team clinic

Patients should be seen within 2 weeks of referral.

Patients with an obvious abdominal mass should be referred for urgent CT CAP scan to determine:
- Definition of probable tumour
- If there is any local / vascular invasion or distant spread

Symptomatic patients in whom an ultrasound has failed to demonstrate an abnormality should be referred for CT scan.

Other investigations:
- Clotting studies
- MRI if other forms of imaging have not adequately demonstrated the extent of the disease.
- ERCP with cytology (see text re stenting). A formal staging CT should be performed prior to any attempts at drainage

Note: Key local contact names and telephone numbers are found in the Kent & Medway MDT Contact List, a copy of which can be located on the KMCC website via the following link:
http://kmcc.nhs.uk/tumour-sites/terms-of-reference/

3.6 Local to Specialist team referrals (notification) and management

Hepatobiliary/Pancreatic malignancies are rarely curable. The following categories of patient should be referred/notified to the King’s team:

3.6.1 Pancreatic Tumours

All patients with resectable pancreatic tumours should be referred to King’s Specialist MDT for opinion:

[a] **Resectable tumour**
Tumours up to 4cm in diameter with no involvement of portal/superior mesenteric vein or artery and with no peritoneal or distant metastases.

[b] **Locally advanced tumours**
These are tumours greater than 4 cm in diameter with up to 50% involvement of the circumference of superior mesenteric or portal vein. These patients should also be referred as some may be offered extended resections involving excision of superior mesenteric and portal vein. Portal vein involvement alone (with the exception of complete occlusion) should be classified as borderline for resection and therefore patients should be referred to the centre MDM. Locally advanced tumours without distant spread or peritoneal mets if their PS is 0-2 should be referred to the centre as they may be eligible for trials (i.e. ESPAC5 and or newer treatments (i.e. IRE) and/or strategies for aggressive down staging with chemo/chemorad.
Unresectable tumours
These are patients with large tumours with more than 50% involvement of superior mesenteric artery, peritoneal and distant metastases or severe co-morbidity. Where possible tissue diagnosis should be sought locally. These patients should be referred only for information, review and audit purposes.

3.6.2 Peri-Ampullary / Ampullary Tumours

Malignant paraduodenal tumours, villous adenomas with dysplastic changes should be referred.

Patients with a “double duct” sign without obvious masses, but who are fit for surgery

3.6.3 Cholangio-carcinoma

Cholangiocarcinoma involving the lower end of the bile duct should be referred.

Few patients in this category are suitable for curative resection. However, extended right or left hepatectomy for hilar cholangiocarcinoma and Whipples procedure for carcinoma of the lower end of the bile duct can be offered to selected patients. The majority of these patients will require ERCP and stent prior to referral. Bilobar stenting is preferable to unilobar stenting.

Note: Uncovered metal stents should not be placed until resection has been excluded as an option.

Resectable hilar cholangiocarcinoma are tumours with or without a mass in the hilum not involving the portal vein or the hepatic artery without evidence of distant metastases should be referred.

Absence of involvement of left lateral segment (segments 2 & 3) alone may sometimes be adequate to offer surgery. Extended resections may be possible for these patients following portal vein embolisation of the right lobe.

Note: if drainage is required, unless the patient is septic when all segments should be drained, drain only segments 2&3.

3.6.4 Hepato-Cellular Tumours (HCC) [with and without associated cirrhosis]

Any patient with HCC should be referred to the specialist unit for active management unless the performance status is too poor to allow anything other than symptom relief.

The majority of these tumours are associated with underlying cirrhosis and these should be referred to the hepatology team for consideration for liver transplantation or chemoembolisation.

Patients with HCC with no underlying liver disease (including fibrolamellar HCC):
Liver resection
Hepatic resection should be considered as primary therapy in any patient with HCC and a non-cirrhotic liver (including fibrolamellar variant). Resection can be carried out in selected patients with hepatic cirrhosis and well preserved hepatic function (Child-Pugh A). Anatomical respectability should be determined by review of imaging at the King’s MDM.

Patients with HCC with underlying cirrhosis:
Liver transplantation
Liver transplantation should be considered as primary therapy in any patient with cirrhosis and small lesion (5cm or less single nodule, or up to five lesions of 3cm or less) or in patients with a single lesion greater than 5cm and less than or equal to 7 cm diameter where there has been no evidence of tumour progression (volume increase by <20%; no extrahepatic spread; no new nodule formation) over a 6 month period.
3.6.5 Neuro-Endocrine Tumours

Neuro-endocrine tumours should be referred to the Specialist MDT.

3.6.6 Non-Cancerous Masses

e.g. Lymphomatous masses for pancreatic biopsy – could be managed locally – but the King’s team should be notified.

3.6.7 Difficult cases

Any of the above tumours about which the local MDT is unsure about management should be discussed with the specialist MDT.

3.6.8 Clinical Trials

- King’s will keep KMCC notified of on-going clinical trials
- MDTs will consider clinical trial entry when discussing patients and recommending (and recording) treatment options

3.6.9 Referral Details

Referrals should be made using the Proformas attached to the end of this document.

Proformas should be faxed to the HPB Central Office: 020 7346 1778

The HPB Central Office will:
  1. Arrange an appointment with the patient in a timescale that will ensure that 31 & 62-day targets are not breached by either the local or specialist team.
  2. Notify the local team AND the patient’s GP of the date of the appointment within 24 hours of the appointment being made. This will include the team to which the patient has been triaged, the name of the team leader and contact details.

Note: Key contact details are found in the Kent & Medway MDT Contact List, a copy of which can be located on the KMCC website via the following link:- http://kmcc.nhs.uk/tumour-sites/terms-of-reference/

The Specialist Team will:
- Review the patient in outpatients or on the ward
- Order further investigations if necessary
- Discuss the patient at MDM and define a treatment plan
- Discuss the treatment plan with the patient
- Communicate the outcomes of the MDM and treatment plan discussions with the patient to the referring clinician and GP within 24 hours of the discussion with the patient
- Undertake agreed potentially curative or palliative surgical procedure and manage any post-operative complications
- Communicate the outcome of surgery to the referring team and GP within 4 working days of the procedure – and [1] certainly before discharge back to the local team, and [2] within 24 hours of any untoward incident.
- Discuss further treatment options with the local team
- Agree any discharge arrangements from specialist to local team BEFORE the patient is discharged
- Agree a follow up schedule (based on the schedule outlined below) with the local team.
**Note:** There must be effective communications between the surgical centre, the local oncology centre, the local specialist Upper GI cancer team, the local specialist palliative care team and the patient’s general practitioner.

- Patients who have been referred to a surgical centre for potentially curative treatment must be referred back to their local centre for any on-going care, whether this be oncological and/or specialist palliation.
- Patients with recurrent disease will receive any appropriate palliation in the local setting providing local expertise is available.
- Patients referred to a surgical centre for potentially curative treatment but who have required specialist palliative care intervention at the centre must be referred back to the local specialist palliative care team.

### 4.0 Oncology specification

Local and specialist MDTs will communicate, on an individual patient basis, on appropriate oncological support for patients.

When local MDTs embark upon oncological treatment programmes (whether within or outside of the context of clinical trials) for patients known to the centre, they will keep the centre informed as to the nature, progress and outcome for individual patients.

The Upper GI Non-Surgical Oncology Group is responsible for defining and maintaining the Non-Surgical Oncological Pathways of Care for Upper GI Cancers.

For further information on oncological management – please refer to “Oncology Treatment of Upper GI Cancers” on the KMCC website: [http://kmcc.nhs.uk/tumour-sites/tumour-site-specific-information/upper-gi-tssg/](http://kmcc.nhs.uk/tumour-sites/tumour-site-specific-information/upper-gi-tssg/)

### 5.0 Palliative Treatment

The aim of palliative care in patients with hepatobiliary cancer is usually relief of jaundice and pain.

Patients with pancreatic cancer and obstructive jaundice should have a biliary stent (preferably a fully covered, removable SEMS) inserted endoscopically at the time of ERCP. This is irrespective of possible surgical resectability. Specimens for brush cytology should be sent in all patients without an established tissue diagnosis. If a stent cannot be placed endoscopically, the patient should be referred to a biliary interventional radiologist for percutaneous stent placement, or via a combined ERCP/percutaneous method. It is rare for these approaches to be unsuccessful, but occasionally biliary bypass surgery will be required.

Patients with potentially resectable pancreatic cancer should not have stents placed prior to referral to the specialist centre while the bilirubin remains below 100. Patients are usually able to tolerate this level of bilirubinaemia well and complications of ERCP may adversely affect the outcome of subsequent surgical management.

Surgical bypass should not be considered unless stenting is unsuccessful.

Patients with established inoperable hilar malignancy should have a palliative treatment plan decided at the MDM. This should aim to:
- Achieve bilobar drainage
- Use SEMs at initial treatment

All patients should be referred to the local palliative care team to ensure good symptom control.
6.0 Specialist Palliative Care and Support

All patients with HPB cancer will have access to specialist palliative care and support at every stage of the patient journey.

Open and frank discussions with patients should take place with patients at all stages of their journey so that patients are not confused about their prognosis or have unrealistic expectations of any of the forms of treatment offered to them.

Relatives and carers will need to be appropriately supported and given appropriate information. However, in accord with the recommendations set out in the revised Improving Outcomes Guidance in Upper GI Cancer, relatives and carers should not be given information different to that given to the patient.

Frail and terminally ill patients with HPB cancer should always be discussed with the specialist palliative care team.

Palliative care provision should be made for all patients:
- Hospital teams, including the Clinical Nurse Specialists for upper GI cancer patients
- Primary Health Care Team would provide for palliative care at home
- General Practitioner should be informed within 24 hours of the diagnosis, treatment plan and medication

The management of symptoms, psychological, social and spiritual issues, and the communication of the diagnosis, and any associated problems, should be within the domain of all health care professionals.

Referral to specialist palliative care services should be considered when these issues have not been resolved and in particular for patients with:
- Complex symptom management issues, which are difficult to manage
- Difficulties in adjusting to the diagnosis or disease progression
- Psychological and family issues – such as communication problems within the family
- Spiritual issues – such as the challenging of belief system/faith/cultural values as a result of the cancer.

Consideration of specialist palliative care or support should be given throughout the patient pathway, particularly:
- At the Multidisciplinary Team Meeting
- When no active treatment is considered
- After active treatment
- At relapse
- In the terminal stages.

All patients should have access to an upper GI cancer nurse specialist who is a member of the specialist upper GI/HPB team cancer.
7.0 Follow Up

7.1 Schedule for patients following palliative surgical intervention

Following palliative intervention, either by the specialist or local team, patients may be reviewed once post-operatively at 3-4 weeks. Patients will then be managed by local clinical nurse specialists, primary care clinicians and the palliative care team. Patients will have unlimited access to clinical nurse specialist support.

The local MDT will ensure that outcomes of local MDT discussions and update on progress will be communicated to the centre.

7.2 Schedule for patients following potentially curative surgery

Following curative surgery, patients will be reviewed by the specialist team 2-4 weeks post operatively. Further follow up should be managed by the local team.

Following discharge to the local team post curative surgery there should be an agreed follow up plan for each patient.

The local MDT will ensure that outcomes of local MDT discussions and update on progress will be communicated to the centre.

7.3 Schedule for patients following adjuvant chemotherapy

Following adjuvant chemotherapy patients will normally be reviewed once by the oncologist and then managed by the clinical nurse specialist, primary care and palliative care teams. Patients will have unlimited access to the clinical nurse specialist.

7.4 Follow Up – general comments

The GI clinical nurse specialist or the community palliative care team would normally be the first line of contact for patients to contact with concerns or about symptom development.

At a medical level follow up should be rationalised so that assessment is carried out by the clinician responsible for a given phase of the patient journey.

Unless specialist “joint clinics” are available patients will not be subjected to parallel follow up by a range of different specialists.

The GI clinical nurse specialist will be best placed to discuss on-going patient care with the clinicians in order that patients receive the most appropriate form of follow up.
8.0 Management of benign/pre-cancerous HPB lesions

MDTs are being referred increasing numbers of patients with benign liver tumours or precancerous HPB lesions. Algorithms to assist clinicians in managing these conditions can be found at:

http://kmcc.nhs.uk/tumour-sites/tumour-site-specific-information/upper-gi-tssg/

9.0 Referral Proforma

A copy of the KMCC Upper GI 2 week wait Referral Proforma is located on the KMCC website and available via the following link:- http://kmcc.nhs.uk/tumour-sites/tumour-site-specific-information/upper-gi-tssg/

10.0 Data

Collection of data at each stage of the pathway is the responsibility of the team looking after the patient at that time. The minimum dataset agreed by the TSSG will be a combination of those data items that meet national requirements, and additional items as agreed by the TSSG.

National data requirements will include:

- Cancer Waiting Times monitoring, including Going Further on Cancer Waits. The data items required will be as defined in ISB0147 at the time of referral and/or treatment.


  Cancer Waiting Times data will be submitted according to the timetable set out in the National Contract for Acute Services.

- The Cancer Outcomes and Services Dataset. The data items will be as defined in ISB1521, and any subsequent versions, at the time of diagnosis and/or treatment. The requirement will include those fields listed in the “Core” section of the dataset, and any additional tumour site specific sections, as applicable.

  Details of the COSD are available from: http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd.aspx

  Cancer Registration and Cancer Outcomes and Services (COSD) data will be submitted according to the timetable set out by National Cancer Registration Service (NCRS).

- Where applicable, teams will also collect additional data items as defined in any corresponding National Clinical Audit Support Programme (NCASP) audit dataset.

  Details of these datasets are available from: http://www.ic.nhs.uk/services/national-clinical-audit-support-programme-ncasp/cancer

  Data for NCASP audits will be submitted, where applicable, according to timetables as agreed by the TSSG, and within the overall submission deadlines for each audit.

Submission of data to meet these national requirements will be the responsibility of each individual Trust.

Note that these standards are subject to variation from time to time, and where these requirements change, the data items required to be collected by the team will also change in line with national requirements.
Local data requirements will include any additional data items as agreed by the TSSG. These must be selected to avoid overlap with any existing data items, and where possible must use standard coding as defined in the NHS Data Dictionary.

Where possible and applicable, InfoFlex will be used for the collection and storage of data. Additional areas of the COSD, relating to pathology, radiotherapy, SACT, diagnostic imaging and basic procedure details will feed into the dataset from other nationally mandated sources. It is the responsibility of each team to ensure that the whole of the relevant dataset is collected, and it is acknowledged that this may come from a variety of sources.

11.0 Glossary

Acronyms in common usage throughout KMCC documentation:

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<tr>
<th>Acronym</th>
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<tr>
<td>CNB</td>
<td>Cancer Network Board</td>
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<tr>
<td>CYP</td>
<td>Children &amp; Young People (in relation to the IOG)</td>
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<tr>
<td>DCCAG</td>
<td>Diagnostic Cross Cutting Advisory Group</td>
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<tr>
<td>DOG</td>
<td>Disease Orientated Group (NSSG/TSSG/TWG)</td>
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<td>DVH</td>
<td>Darent Valley Hospital</td>
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<td>EK</td>
<td>East Kent</td>
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<tr>
<td>EKHUFT</td>
<td>East Kent Hospitals University Foundation Trust</td>
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<tr>
<td>HoP</td>
<td>High Level Operational Policy</td>
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<tr>
<td>IOSC</td>
<td>Improving Outcomes: A Strategy for Cancer</td>
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<tr>
<td>K&amp;C</td>
<td>Kent &amp; Canterbury Hospital, Canterbury, (EKHUFT)</td>
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<tr>
<td>KMCC</td>
<td>Kent &amp; Medway Cancer Collaborative</td>
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<tr>
<td>KMCRN</td>
<td>Kent &amp; Medway Cancer Research Network</td>
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<tr>
<td>LSESN</td>
<td>London &amp; South East Sarcoma Network</td>
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<tr>
<td>MFT</td>
<td>Medway Foundation Trust</td>
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<tr>
<td>MTW</td>
<td>Maidstone &amp; Tunbridge Wells NHS Trust</td>
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<td>NOG</td>
<td>Non Surgical Oncology Group (Permanent oncologist sub group of the TSSGs with a specific responsibility for chemo/rad pathways and advice to the TSSG, KMCC and geographical locations on new drugs)</td>
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<td>PoC</td>
<td>Pathway of Care (KMCC agreed disease site specific clinical guidelines)</td>
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<td>QEQM</td>
<td>Queen Elizabeth the Queen Mother Hospital, Margate (EKHUFT)</td>
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<td>QoL</td>
<td>Quality of life</td>
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<tr>
<td>RAT</td>
<td>Research and Trial Group (Permanent sub-group of the TSSGs with a specific responsibility for taking forward the clinical trials agenda)</td>
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<td>TSSG</td>
<td>Tumour Site Specific Group</td>
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12.0 Personnel and Contact Information

A comprehensive, up to date list of MDM contact details can be found on the KMCC website via the following link: [http://kmcc.nhs.uk/tumour-sites/terms-of-reference/](http://kmcc.nhs.uk/tumour-sites/terms-of-reference/)
12.0 Document Administration

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<td>October 2015</td>
<td>3.3</td>
<td>Updated with changes from circulating to the UGI TSSG</td>
<td>A.Piotrowicz</td>
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<tr>
<td>March 2016</td>
<td>4.0</td>
<td>Final Published following O&amp;Q ratification – minor grammatical changes noted</td>
<td>N.Aluwalia</td>
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<tr>
<td>September 2016</td>
<td>4.1</td>
<td>Further review, weblinks updated. Content checked</td>
<td>N.Aluwalia/A.Piotrowicz</td>
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<tr>
<td>March 2017</td>
<td>4.2</td>
<td>Amendments to palliative treatment and addition of section 8 for guidance on the management of benign/precancerous lesions. TSSG ratification to be completed at meeting on 30/3/17.</td>
<td>A.Piotrowicz</td>
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<tr>
<td>May 2017</td>
<td>5.0</td>
<td>Amendments made following O&amp;Q Group ratification. Final published version</td>
<td>O&amp;Q Group / N.Aluwalia</td>
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