



PAPER DATA COLLECTION FORM

Record ID

Form filled by

Hospital

OpenPseudonymiser number

Obtain from inputting NHS number into OpenPseudonymiser program

INCLUSION one of question 1-3 should be answered with **Yes** to enter the study

1. Suspected malignant pancreatic or peri-ampullary lesion? ☐ Yes ☐ No
2. Biliary obstruction caused by a suspected primary malignancy of liver hilum or extrahepatic biliary tree? ☐ Yes ☐ No

EXCLUSION If one of questions 4-7 is answered with **Yes**, the patient should be excluded

4. Patient age <16 years ☐ Yes ☐ No
5. Recurrent HPB malignancy? ☐ Yes ☐ No
6. Suspected secondary malignancy (metastasis)? ☐ Yes ☐ No
7. Gallbladder or intrahepatic lesion? ☐ Yes ☐ No

PATIENT FACTORS

8. Mode of presentation

Outpatient dept. (2WW) ☐ Emergency admission via GP ☐ Emergency admission via A&E ☐
 Outpatient dept. (non-2WW) ☐ Incidental radiological ☐

9. Date of first hospital contact ___ - ___ - ____ (dd-mm-yyyy)

10. Final date of 90 day follow-up ___ - ___ - ____ (dd-mm-yyyy)

11. Age at presentation ___ years

12. Gender Female ☐ Male ☐

13. Body Mass Index ___ kg/m²

14. Comorbidities

AIDS	<input type="checkbox"/>	Cerebrovascular disease	<input type="checkbox"/>	Chronic liver disease	<input type="checkbox"/>
Chronic lung disease	<input type="checkbox"/>	Congestive heart failure	<input type="checkbox"/>	Connective tissue disease	<input type="checkbox"/>
Dementia	<input type="checkbox"/>	Diabetes mellitus	<input type="checkbox"/>	Diabetes with end organ damage	<input type="checkbox"/>
Hemiplegia	<input type="checkbox"/>	Leukaemia	<input type="checkbox"/>	Lymphoma	<input type="checkbox"/>
Metastatic cancer	<input type="checkbox"/>	Moderate/severe kidney disease	<input type="checkbox"/>	Moderate/severe liver disease	<input type="checkbox"/>
Myocardial	<input type="checkbox"/>	Peptic ulcer disease	<input type="checkbox"/>	Peripheral vascular disease	<input type="checkbox"/>

15. Performance status - As recorded from MDT or from your assessment of the patient/notes.

0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

16. Baseline eGFR ___ ml/min/1.73m²

Value >4 weeks prior to presentation.

17. Date baseline eGFR ___ - ___ - ____ (dd-mm-yyyy)

MULTIDISCIPLINARY TEAM MEETING (MDT)

MDT 1

18.1 Date

___ - ___ - ____ (dd-mm-yyyy)

18.2 TNM stage recorded at MDT?

Yes

☐

No

☐

18.3 MDT classification of tumour



Resectable	<input type="checkbox"/>	Unresectable	<input type="checkbox"/>	Further investigation required	<input type="checkbox"/>
A, If Resectable, is the patient...Fit for surgery	<input type="checkbox"/>	Unfit for surgery	<input type="checkbox"/>	Need further assessment	<input type="checkbox"/>
B, If Unresectable, is this because of... Metastatic disease	<input type="checkbox"/>	Locally advanced disease	<input type="checkbox"/>	Pt fitness	<input type="checkbox"/>
C, If further investigation, is this to... Determine the nature of lesion	<input type="checkbox"/>	Determine the extent of lesion	<input type="checkbox"/>		<input type="checkbox"/>
18.5 Advice of MDT 1					
Palliative treatment – oncology opinion for palliative chemotherapy	<input type="checkbox"/>	Surgery	<input type="checkbox"/>		<input type="checkbox"/>
Palliative treatment – best supportive care	<input type="checkbox"/>	Referral to specialist HPB MDT	<input type="checkbox"/>		<input type="checkbox"/>
Consider for neo-adjuvant therapy (chemo- and/or radiotherapy)	<input type="checkbox"/>	Further investigation	<input type="checkbox"/>		<input type="checkbox"/>
18.6 Did the patient have biliary obstruction at the time of MDT 1 discussion?					
<input type="radio"/> Yes	<input type="radio"/> No	As determined radiologically +/- biochemically			
18.7 Was biliary decompression recommended?					
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not clinically indicated	<input type="checkbox"/>
If no, was this due to-Pt too frail	<input type="checkbox"/>	Technical factors(Likely failure/burden of disease)	<input type="checkbox"/>	Already performed Pt on 'Fast-track' pathway	<input type="checkbox"/>
18.8 If the patient has been referred to another trust, please write the name of this trust/hospital:					

18.9 Was the patient discussed at a later MDT in your hospital?

☐ Yes ☐ No

If No → please go to question

MDT 2	18.1 Date	__ - __ - __ (dd-mm-yyyy)			
18.2 TNM stage recorded at MDT?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	
18.3 MDT classification of tumour					
Resectable	<input type="checkbox"/>	Unresectable	<input type="checkbox"/>	Further investigation required	<input type="checkbox"/>
A, If Resectable, is the patient...Fit for surgery	<input type="checkbox"/>	Unfit for surgery	<input type="checkbox"/>	Need further assessment	<input type="checkbox"/>
B, If Unresectable, is this because of... Metastatic disease	<input type="checkbox"/>	Locally advanced disease	<input type="checkbox"/>	Pt fitness	<input type="checkbox"/>
C, If further investigation, is this to... Determine the nature of lesion	<input type="checkbox"/>	Determine the extent of lesion	<input type="checkbox"/>		<input type="checkbox"/>
18.5 Advice of MDT 1					
Palliative treatment – oncology opinion for palliative chemotherapy	<input type="checkbox"/>	Surgery	<input type="checkbox"/>		<input type="checkbox"/>
Palliative treatment – best supportive care	<input type="checkbox"/>	Referral to specialist HPB MDT	<input type="checkbox"/>		<input type="checkbox"/>
Consider for neo-adjuvant therapy (chemo- and/or radiotherapy)	<input type="checkbox"/>	Further investigation	<input type="checkbox"/>		<input type="checkbox"/>
18.6 Did the patient have biliary obstruction at the time of MDT 1 discussion?					
<input type="radio"/> Yes	<input type="radio"/> No	As determined radiologically +/- biochemically			
18.7 Was biliary decompression recommended?					
Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Not clinically indicated	<input type="checkbox"/>
If no, was this due to-Pt too frail	<input type="checkbox"/>	Technical factors(Likely failure/burden of disease)	<input type="checkbox"/>	Already performed Pt on 'Fast-track' pathway	<input type="checkbox"/>
18.8 If the patient has been referred to another trust, please write the name of this trust/hospital:					

18.9 Was the patient discussed at a later MDT in your hospital?

☐ Yes ☐ No

If No → please go to question

MDT 3	18.1 Date	__ - __ - __ (dd-mm-yyyy)			
18.2 TNM stage recorded at MDT?	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	
18.3 MDT classification of tumour					
Resectable	<input type="checkbox"/>	Unresectable	<input type="checkbox"/>	Further investigation required	<input type="checkbox"/>
A, If Resectable, is the patient...Fit for surgery	<input type="checkbox"/>	Unfit for surgery	<input type="checkbox"/>	Need further assessment	<input type="checkbox"/>
B, If Unresectable, is this because of... Metastatic disease	<input type="checkbox"/>	Locally advanced disease	<input type="checkbox"/>	Pt fitness	<input type="checkbox"/>



C, If further investigation, is this to... Determine the nature of lesion ☐ Determine the extent of lesion ☐

18.5 Advice of MDT 1

Palliative treatment – oncology opinion for palliative chemotherapy ☐ Surgery ☐

Palliative treatment – best supportive care ☐ Referral to specialist HPB MDT ☐

Consider for neo-adjuvant therapy (chemo- and/or radiotherapy) ☐ Further investigation ☐

18.6 Did the patient have biliary obstruction at the time of MDT 1 discussion?

☐ Yes ☐ No *As determined radiologically +/- biochemically*

18.7 Was biliary decompression recommended?

Yes ☐ No ☐ Not clinically indicated ☐ Already performed ☐

If no, was this due to-Pt too frail ☐ Technical factors(Likely failure/burden of disease) ☐ Pt on 'Fast-track' pathway ☐

18.8 If the patient has been referred to another trust, please write the name of this trust/hospital:

18.9 Was the patient discussed at a later MDT in your hospital?

☐ Yes ☐ No

If No → please go to question

MDT 4	18.1 Date	__ - __ - __ (dd-mm-yyyy)	
18.2 TNM stage recorded at MDT?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
18.3 MDT classification of tumour	Resectable <input type="checkbox"/>	Unresectable <input type="checkbox"/>	Further investigation required <input type="checkbox"/>
A, If Resectable, is the patient...Fit for surgery	<input type="checkbox"/> Fit for surgery	<input type="checkbox"/> Unfit for surgery	<input type="checkbox"/> Need further assessment
B, If Unresectable, is this because of... Metastatic disease	<input type="checkbox"/> Metastatic disease	<input type="checkbox"/> Locally advanced disease	<input type="checkbox"/> Pt fitness
C, If further investigation, is this to... Determine the nature of lesion	<input type="checkbox"/> Determine the nature of lesion	<input type="checkbox"/> Determine the extent of lesion	
18.5 Advice of MDT 1			
Palliative treatment – oncology opinion for palliative chemotherapy	<input type="checkbox"/> Surgery		
Palliative treatment – best supportive care	<input type="checkbox"/> Referral to specialist HPB MDT		
Consider for neo-adjuvant therapy (chemo- and/or radiotherapy)	<input type="checkbox"/> Further investigation		
18.6 Did the patient have biliary obstruction at the time of MDT 1 discussion?			
<input type="radio"/> Yes <input type="radio"/> No <i>As determined radiologically +/- biochemically</i>			
18.7 Was biliary decompression recommended?			
Yes <input type="checkbox"/> No <input type="checkbox"/> Not clinically indicated <input type="checkbox"/> Already performed <input type="checkbox"/>			
If no, was this due to-Pt too frail <input type="checkbox"/> Technical factors(Likely failure/burden of disease) <input type="checkbox"/> Pt on 'Fast-track' pathway <input type="checkbox"/>			
18.8 If the patient has been referred to another trust, please write the name of this trust/hospital:			

18.9 Was the patient discussed at a later MDT in your hospital?

☐ Yes ☐ No

If No → please go to question

INVESTIGATIONS

Investigation 1

22.1 Modality

USS ☐ MRI ☐ CT ☐ EUS ☐ PET CT ☐ PTC ☐ ERCP ☐

22.2 Date of investigation

__ - __ - __ (dd-mm-yyyy)

22.3 Was tissue sampling performed?

Yes ☐ No ☐ *If No → please go to question ...*

22.4 What type of tissue sampling?

EUS FNA ☐ ERCP brushing ☐ Tissue biopsy ☐

22.5 Outcome of tissue sampling?

Benign ☐ Not diagnostic ☐ Suspicious ☐ Malignant ☐

22.6 Further investigation? Yes ☐ No ☐

Investigation 2

22.1 Modality

USS ☐ MRI ☐ CT ☐ EUS ☐ PET CT ☐ PTC ☐ ERCP ☐

22.2 Date of investigation ____ - ____ - ____ (dd-mm-yyyy)

22.3 Was tissue sampling performed? Yes ☐ No ☐ If No → please go to question ...

22.4 What type of tissue sampling? EUS FNA ☐ ERCP brushing ☐ Tissue biopsy ☐

22.5 Outcome of tissue sampling?

Benign ☐ Not diagnostic ☐ Suspicious ☐ Malignant ☐

22.6 Further investigation? Yes ☐ No ☐

Investigation 3

22.1 Modality

USS ☐ MRI ☐ CT ☐ EUS ☐ PET CT ☐ PTC ☐ ERCP ☐

22.2 Date of investigation ____ - ____ - ____ (dd-mm-yyyy)

22.3 Was tissue sampling performed? Yes ☐ No ☐ If No → please go to question ...

22.4 What type of tissue sampling? EUS FNA ☐ ERCP brushing ☐ Tissue biopsy ☐

22.5 Outcome of tissue sampling?

Benign ☐ Not diagnostic ☐ Suspicious ☐ Malignant ☐

22.6 Further investigation? Yes ☐ No ☐

Investigation 4

22.1 Modality

USS ☐ MRI ☐ CT ☐ EUS ☐ PET CT ☐ PTC ☐ ERCP ☐

22.2 Date of investigation ____ - ____ - ____ (dd-mm-yyyy)

22.3 Was tissue sampling performed? Yes ☐ No ☐ If No → please go to question ...

22.4 What type of tissue sampling? EUS FNA ☐ ERCP brushing ☐ Tissue biopsy ☐

22.5 Outcome of tissue sampling?

Benign ☐ Not diagnostic ☐ Suspicious ☐ Malignant ☐

22.6 Further investigation? Yes ☐ No ☐

BILIARY DECOMPRESSION

26. Was there an attempt to decompress the biliary tree? Yes ☐ No ☐

If No → please go to question ...

27. By the end of the follow-up period, has decompression been achieved? Yes ☐ No ☐

Biliary decompression procedure 1

28.1 Which procedure was performed? ☐ ERCP ☐ PTC

28.2 Was this procedure in-patient or out-patient? ☐ In-patient ☐ Out-patient

28.3 Date of procedure 1 ____ - ____ - ____ (dd-mm-yyyy)

28.4 What was the last serum bilirubin BEFORE this attempt to decompress? ____ μmol/L

28.5 What was the last eGFR BEFORE this attempt to decompress? ____ ml/min/1.73m²

28.6 Was the decompression performed in the circumstance of cholangitis? Yes ☐ No ☐

28.7 Were peri-procedural IV-fluids given? Yes ☐ No ☐



28.8 Were peri-procedural antibiotics given? (within 48h around procedure)

- ☐ Yes, prophylaxis ☐ Yes, therapeutic ☐ No

28.9 Was nephrotoxic medication paused?

- ☐ Yes ☐ No ☐ Patient was not on any nephrotoxic medication

Examples: NSAIDS (e.g. ibuprofen); ACEi (lisinopril, perindopril), Angiotensin Receptor Blockers (losartan, valsartan); Note - this is not an exhaustive list and clinical discretion is required.

28.10 Was a rectal NSAID prescribed peri-procedurally?

Yes ☐ No ☐

28.11 Were there any post-intervention complications? (More than one answer possible)

None <input type="checkbox"/>	Bleeding (requiring transfusion of intervention) <input type="checkbox"/>	Perforation <input type="checkbox"/>
Cholangitis <input type="checkbox"/>	Pancreatitis (3x baseline amylase with abdominal pain) <input type="checkbox"/>	Pneumothorax <input type="checkbox"/>
Acute kidney injury (>1.5x increase in baseline serum creatinine) <input type="checkbox"/>		

28.12 Did one of these complication required surgical, radiological or endoscopic intervention?

- ☐ Yes ☐ No

28.13 Did the patient die as a result of this complication?

- ☐ Yes ☐ No

28.14 Was the decompression successful? (as decided by the operator's comments in procedural notes)

- ☐ Yes ☐ No *If Yes → please go to question*

28.15 Was the patient readmitted within 7 days of the procedure?

Yes ☐ No ☐

28.16 Why was the decompression unsuccessful?

- ☐ Unable to cannulate ☐ Unable to deploy stent ☐ Other

Biliary decompression procedure 2

28.1 Which procedure was performed?

- ☐ ERCP ☐ PTC

28.2 Was this procedure in-patient or out-patient?

- ☐ In-patient ☐ Out-patient

28.3 Date of procedure 2 ____ - ____ - ____ (dd-mm-yyyy)

28.4 What was the last serum bilirubin BEFORE this attempt to decompress?

____ μmol/L

28.5 What was the last eGFR BEFORE this attempt to decompress?

____ ml/min/1.73m²

28.6 Was the decompression performed in the circumstance of cholangitis?

Yes ☐ No ☐

28.7 Were peri-procedural IV-fluids given?

Yes ☐ No ☐

28.8 Were peri-procedural antibiotics given? (within 48h around procedure)

- ☐ Yes, prophylaxis ☐ Yes, therapeutic ☐ No

28.9 Was nephrotoxic medication paused?

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Yes ☐ No ☐

28.11 Were there any post-intervention complications? (More than one answer possible)

None <input type="checkbox"/>	Bleeding (requiring transfusion of intervention) <input type="checkbox"/>	Perforation <input type="checkbox"/>
Cholangitis <input type="checkbox"/>	Pancreatitis (3x baseline amylase with abdominal pain) <input type="checkbox"/>	Pneumothorax <input type="checkbox"/>
Acute kidney injury (>1.5x increase in baseline serum creatinine) <input type="checkbox"/>		

28.12 Did one of these complication required surgical, radiological or endoscopic intervention?

- ☐ Yes ☐ No

28.13 Did the patient die as a result of this complication?

- ☐ Yes ☐ No

28.14 Was the decompression successful? (as decided by the operator's comments in procedural notes)

- ☐ Yes ☐ No *If Yes → please go to question*

28.15 Was the patient readmitted within 7 days of the procedure?

Yes ☐ No ☐



28.16 Why was the decompression unsuccessful?

- ☐ Unable to cannulate ☐ Unable to deploy stent ☐ Other

Biliary decompression procedure 3

28.1 Which procedure was performed?

- ☐ ERCP ☐ PTC

28.2 Was this procedure in-patient or out-patient?

- ☐ In-patient ☐ Out-patient

28.3 Date of procedure 3 ____ - ____ - ____ (dd-mm-yyyy)

28.4 What was the last serum bilirubin BEFORE this attempt to decompress?

____ $\mu\text{mol/L}$

28.5 What was the last eGFR BEFORE this attempt to decompress?

____ ml/min/1.73m^2

28.6 Was the decompression performed in the circumstance of cholangitis?

Yes ☐ No ☐

28.7 Were peri-procedural IV-fluids given?

Yes ☐ No ☐

28.8 Were peri-procedural antibiotics given? (within 48h around procedure)

- ☐ Yes, prophylaxis ☐ Yes, therapeutic ☐ No

28.9 Was nephrotoxic medication paused?

- ☐ Yes ☐ No ☐ Patient was not on any nephrotoxic medication

Examples: NSAIDs (e.g. ibuprofen); ACEi (lisinopril, perindopril), Angiotensin Receptor Blockers (losartan, valsartan); Note - this is not an exhaustive list and clinical discretion is required.

28.10 Was a rectal NSAID prescribed peri-procedurally?

Yes ☐ No ☐

28.11 Were there any post-intervention complications? (More than one answer possible)

None ☐ Bleeding (requiring transfusion of intervention) ☐ Perforation ☐

Cholangitis ☐ Pancreatitis (3x baseline amylase with abdominal pain) ☐ Pneumothorax ☐

Acute kidney injury (>1.5x increase in baseline serum creatinine) ☐

28.12 Did one of these complication required surgical, radiological or endoscopic intervention?

- ☐ Yes ☐ No

28.13 Did the patient die as a result of this complication?

- ☐ Yes ☐ No

28.14 Was the decompression successful? (as decided by the operator's comments in procedural notes)

- ☐ Yes ☐ No *If Yes → please go to question ...*

28.15 Was the patient readmitted within 7 days of the procedure?

Yes ☐ No ☐

28.16 Why was the decompression unsuccessful?

- ☐ Unable to cannulate ☐ Unable to deploy stent ☐ Other

SURGERY

31. Was curative surgery attempted?

Yes ☐ No ☐ On the waiting list ☐

If No or Awaiting → please go to question ...

32. What was the initial planned date of surgery?

____ - ____ - ____ (dd-mm-yyyy)

33. Did surgery happen on the initial planned date?

Yes ☐ No ☐

If Yes → please go to question ...

34. If surgery was initially postponed, what was the reason?

- ☐ Patient factors ☐ Bed availability / institutional factors ☐ Other

35. What was the actual date of surgery?

____ - ____ - ____ (dd-mm-yyyy)

36. What operation was performed?

Pancreaticoduodenectomy (PPPD / Whipple) ☐ Hepatectomy + excision of extrahepatic ☐

Distal pancreatectomy ☐ biliary tree ☐

Total pancreatectomy ☐ Curative procedure abandoned ☐



Subtotal pancreatectomy

☐ Other

Central pancreatectomy

☐If answered **Curative procedure abandoned** → please go to question ..., otherwise go to

37. If abandoned, what operation was performed?

Gastrojejunostomy

☐

Hepaticojejunostomy

☐

Open and close

☐

Other

☐

38. Why was the procedure abandoned?

Metastatic disease

☐

Locally advanced

☐

Other

39. Was a vascular resection performed?

Yes

☐

No

☐**PATHOLOGY**

40. What was the pathological type of malignancy? (Histological confirmation is required)

Pancreatic adenocarcinoma

☐

Neuroendocrine tumour

☐

Ampullary adenocarcinoma

☐

Intraductal papillary mucinous neoplasm

☐

Cholangiocarcinoma

☐

Duodenal

☐

Other

42.1 Tumour

T0

Tis

T1

T2

T3

T4

42.2 Nodes

N0

N1

42.3 Metastasis

M0

M1

ADDITIONAL & SUPPORTIVE CARE

43. Does the patient have unresectable disease?

Yes

☐

No

☐

44. Has the patient been seen by a Clinical Nurse Specialist (CNS)?

Yes

☐

No

☐

45. Have pancreatic enzyme supplements been prescribed? (e.g. Creon)

Yes

☐

No

☐

46. Has acid suppression been prescribed? (e.g. PPI / H2-antagonist)

Yes

☐

No

☐

47. Has the patient been referred to a dietician?

Yes

☐

No

☐

48. If the patient was admitted, has the Malnutrition Universal Screening Tool

Yes

☐

No

☐

49. Have nutritional supplements been prescribed?

Yes

☐

No

☐

50. Is there evidence of a discussion about a ceiling of care or resuscitation?

Yes

☐

No

☐**90 DAY OUTCOMES**

51. Was there an emergency admission following the first presentation?

o Yes

o No

52. What was the total number of in-patient days within the 90 day follow-up period?

___ days

53. What is the 90 day outcome for this patient?

Awaiting neo-adjuvant therapy

☐

Resected with curative intent, disease free at 90 day f/u

☐

Started neo-adjuvant therapy

☐

Resected with curative intent, recurrence within 90 day f/u

☐

Intra-operatively unresectable

☐

Awaiting palliative chemotherapy

☐

Best supportive care

☐

Started palliative therapy

☐o If **Death**, What was the date of death (within 90 days follow up)

55. Form complete?

Yes

☐

No

☐