

## PAPER DATA COLLECTION FORM

Record ID				
Form filled by				
Hospital				
OpenPseudonymiser number	btain from inputting NHS nu	mber into Oper	nPseudonymiser progran	1
<b>INCLUSION</b> one of question 1-3 should	be answered with <b>Yes</b> to ente	r the study		
1. Suspected malignant pancreatic or p	peri-ampullary lesion?	o Yes	o No	
2. Biliary obstruction caused by a susp of liver hilum or extrahepatic biliary tr		o Yes	o No	
<b>EXCLUSION</b> If one of questions 4-7 is a	nswered with <b>Yes</b> , the patient	should be exclu	ıded	
4. Patient age <16 years		o Yes	o No	
5. Recurrent HPB malignancy?		o Yes	o No	
6. Suspected secondary malignancy (m	netastasis)?	o Yes	o No	
7. Gallbladder or intrahepatic lesion?		o Yes	o No	
PATIENT FACTORS				
Outpatient dept. (non-2WW)  9. Date of first hospital contact  10. Final date of 90 day follow-up  11. Age at presentation  12. Gender  13. Body Mass Index  14. Comorbidities  AIDS  Chronic lung disease  Dementia  Hemiplegia  Congestive  Diabetes m  Leukaemia	severe kidney disease	Male  Chronic live Connective Diabetes w Lymphoma Moderate/	e tissue disease vith end organ damage	
,	rom MDT or from your assessi  2 3  /min/1.73m <sup>2</sup> (dd-mm-yyyy)	4	tent/notes.  5  ks prior to presentation.	
MULTIDISCIPLINARY TEAM MEE				
MDT 1	18.1 Date	(d	d-mm-yyyy)	
18.2 TNM stage recorded at MDT? 18.3 MDT classification of tumour	Yes No			



Resectable	Unresectable Further investigation required	
A, If Resectable, is the patientFit for sur	rgery Unfit for surgery Need further assessment	
B, If Unresectable, is this because of Me		
C, If further investigation, is this to Det		
9	Determine the nature of lesion	
18.5 Advice of MDT 1		
Palliative treatment – oncology opinion f	<b>├</b>	
Palliative treatment – best supportive ca	Referral to specialist HPB MDT	
Consider for neo-adjuvant therapy (chen	mo- and/or radiotherapy) Further investigation	
18.6 Did the patient have biliary obstruc	ction at the time of MDT 1 discussion?	
o Yes o No	As determined radiologically +/- biochemically	
18.7 Was biliary decompression recomm		
	Not clinically indicated Already performed	
	ical factors(Likely failure/burden of disease)  Pt on 'Fast-track'	
frail	pathway	
18.8 If the patient has been referred to a	nother trust, please write the name of this trust/hospital:	
18.9 Was the patient discussed at a later	MDT in your hospital?	_
o Yes o No	If <b>No →</b> please go to question	
MDT 2	<b>18.1 Date</b> (dd-mm-yyyy)	_
18.2 TNM stage recorded at MDT?	Yes No	_
18.3 MDT classification of tumour		
	II	
Resectable	Unresectable Further investigation required	
A, If Resectable, is the patientFit for sur	rgery Unfit for surgery Need further assessment	
_		
B, If Unresectable, is this because of Me		
B, If Unresectable, is this because of Me C, If further investigation, is this to Det	etastatic disease Locally advanced disease Pt fitness	
	etastatic disease Locally advanced disease Pt fitness	
C, If further investigation, is this to Det 18.5 Advice of MDT 1	etastatic disease Locally advanced disease Pt fitness termine the nature of lesion Determine the extent of lesion	
C, If further investigation, is this to Det 18.5 Advice of MDT 1 Palliative treatment – oncology opinion for	etastatic disease Locally advanced disease Pt fitness termine the nature of lesion Determine the extent of lesion for palliative chemotherapy Surgery	
C, If further investigation, is this to Det 18.5 Advice of MDT 1 Palliative treatment – oncology opinion for Palliative treatment – best supportive ca	etastatic disease Locally advanced disease Pt fitness termine the nature of lesion Determine the extent of lesion  for palliative chemotherapy Surgery Referral to specialist HPB MDT	
C, If further investigation, is this to Det 18.5 Advice of MDT 1 Palliative treatment – oncology opinion for Palliative treatment – best supportive ca Consider for neo-adjuvant therapy (chem	termine the nature of lesion  Determine the extent of lesion  for palliative chemotherapy are  Morand/or radiotherapy  Further investigation	
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C, If further investigation, is this to Det 18.5 Advice of MDT 1  Palliative treatment – oncology opinion of Palliative treatment – best supportive ca Consider for neo-adjuvant therapy (chem 18.6 Did the patient have biliary obstruction of Yes of No No 18.7 Was biliary decompression recommands of No If no, was this due to-Pt too of Technification of Yes of No No No MDT 3  18.9 Was the patient discussed at a later of Yes of No No MDT 3  18.2 TNM stage recorded at MDT?	termine the nature of lesion Determine the extent of lesion  for palliative chemotherapy Referral to specialist HPB MDT mo- and/or radiotherapy) Further investigation ction at the time of MDT 1 discussion?  As determined radiologically +/- biochemically mended?  Not clinically indicated Already performed ical factors(Likely failure/burden of disease) Pt on 'Fast-track' pathway mother trust, please write the name of this trust/hospital:  MDT in your hospital?  If No → please go to question	
C, If further investigation, is this to Det 18.5 Advice of MDT 1  Palliative treatment – oncology opinion of Palliative treatment – best supportive cat Consider for neo-adjuvant therapy (chem 18.6 Did the patient have biliary obstruction of Yes No	termine the nature of lesion Determine the extent of lesion  for palliative chemotherapy Referral to specialist HPB MDT mo- and/or radiotherapy Further investigation ction at the time of MDT 1 discussion?  As determined radiologically +/- biochemically mended?  Not clinically indicated Already performed performed ical factors(Likely failure/burden of disease) Pt on 'Fast-track' pathway mother trust, please write the name of this trust/hospital:  **If No → please go to question*  18.1 Date (dd-mm-yyyy)  Yes No	
C, If further investigation, is this to Det 18.5 Advice of MDT 1  Palliative treatment – oncology opinion of Palliative treatment – best supportive ca Consider for neo-adjuvant therapy (chen 18.6 Did the patient have biliary obstruct  O Yes O No 18.7 Was biliary decompression recomm Yes No If no, was this due to-Pt too Techni frail 18.8 If the patient has been referred to a  18.9 Was the patient discussed at a later  O Yes O No  MDT 3  18.2 TNM stage recorded at MDT? 18.3 MDT classification of tumour Resectable	terastatic disease	
C, If further investigation, is this to Det 18.5 Advice of MDT 1  Palliative treatment – oncology opinion of Palliative treatment – best supportive cat Consider for neo-adjuvant therapy (chem 18.6 Did the patient have biliary obstruction of Yes No	terastatic disease	



C, If further investigation, is this to	. Determine the nature of lesion	Determine	the extent of lesion	
18.5 Advice of MDT 1	ion for nalliative about 4th annua	Commons		
Palliative treatment – oncology opin		Surgery	an a siglist HDD MDT	
Palliative treatment – best supportive		<b></b>	specialist HPB MDT	
Consider for neo-adjuvant therapy (		Further inv	restigation	
18.6 Did the patient have biliary obs			11	
O Yes O No	As determined radiologicall	y +/- biochemica	lly	
18.7 Was biliary decompression rec		n dianto d	Almondry monformed	
Yes No If no, was this due to-Pt too	Not clinically i	-	Already performed Pt on 'Fast-track'	
frail	echnical factors(Likely failure/burde	n of disease)	pathway	
18.8 If the patient has been referred	to another trust, please write the	 name of this tru	] -	
10.0 if the patient has been referred	to another trust, preuse write the	indiffic of this tre	ist/ iiospitai.	
18.9 Was the patient discussed at a	ater MDT in your hospital?			
o Yes o No		If <b>No →</b> plea	se go to question	
MDT 4	18.1 Date		ım-yyyy)	
18.2 TNM stage recorded at MDT?	Yes No			
18.3 MDT classification of tumour	Tes No			
Resectable	Unresectable	Further in	nvestigation required	
A, If Resectable, is the patientFit for			further assessment	
B, If Unresectable, is this because of		ally advanced dis		
C, If further investigation, is this to	<u> </u>	<del></del>	the extent of lesion	
18.5 Advice of MDT 1	. Determine the nature of resion	Determine	the extent of resion	
Palliative treatment – oncology opir	ion for palliative chemotherapy	Surgery		
Palliative treatment – best supportive		<b>—</b>	specialist HPB MDT	
Consider for neo-adjuvant therapy (		Further inv	-	
18.6 Did the patient have biliary obs				
o Yes o No	As determined radiologicall		lly	
18.7 Was biliary decompression rec		,		
Yes No	Not clinically i	ndicated	Already performed	
If no, was this due to-Pt too	echnical factors(Likely failure/burde		Pt on 'Fast-track'	
frail			pathway	
18.8 If the patient has been referred	to another trust, please write the	name of this tru	st/hospital:	
18.9 Was the patient discussed at a	ater MDT in your hospital?			
o Yes o No		If <b>No →</b> plea	se go to question	
INVESTIGATIONS				
Investigation 1				
22.1 Modality				
USS MRI CT	EUS PET C	т РТС	ERCP	
22.2 Date of investigation	(dd-mm-yyyy	<u> </u>		_
22.3 Was tissue sampling performed?	Yes No	If <b>No →</b> please g	o to question	
22 1 What type of tissue sampling?	FLIS ENIA ERCP brushin	ισ	Tissue hionsy	1 1



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)	
	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	1
USS MRI CT EUS PET CT	PTC ERCP
22.2 Date of investigation (dd-mm-yyyy)	alanca na ta avestian
	please go to question
22.4 What type of tissue sampling? EUS FNA ERCP brushing 22.5 Outcome of tissue sampling?	Tissue biopsy
Benign Not diagnostic Suspicious	Malignant
22.6 Further investigation? Yes No	Wanghant
Investigation 4	
22.1 Modality	
USS MRI CT EUS PET CT	PTC ERCP
22.2 Date of investigation (dd-mm-yyyy)	
	olease 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	
BILLARY DECOMPRESSION	
BILIARY DECOMPRESSION	
26. Was there an attempt to decompress the biliary tree?	Yes No
If <b>No →</b> 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? O ERCP	o PTC
28.2 Was this procedure in-patient or out-patient?	<ul> <li>Out-patient</li> </ul>
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/1.73m <sup>2</sup>
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)	
<ul> <li>Yes, prophylaxis</li> <li>Yes, therapeutic</li> <li>No</li> </ul>	
28.9 Was nephrotoxic medication paused?	
<ul> <li>Yes</li> <li>No</li> <li>Patient was not on any nephrotoxic medication</li> </ul>	
Examples: NSAIDS (e.g. ibuprofen); ACEi (lisinopril, perindopril), Angiotensin Receptor Blockers (losartan, valsartan); Note - this in not an exhaustive list and clinical discretion is required.	s
28.10 Was a rectal NSAID prescribed peri-procedurally?	
28.11 Were there any post-intervention complications? (More than one answer possible)	
None Bleeding (requiring transfusion of intervention) Perforation	
Cholangitis Pancreatitis (3x baseline amylasis 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?	
o Yes o No	
28.13 Did the patient die as a result of this complication?	
o Yes o No	
28.14 Was the decompression successful? (as decided by the operator's comments in procedural notes)	
$\circ$ Yes $\circ$ No If <b>Yes</b> $\rightarrow$ please go to question	
28.15 Was the patient readmitted within 7 days of the procedure?	
28.16 Why was the decompression unsuccessful?	
<ul> <li>Unable to cannulate</li> <li>Unable to deploy stent</li> <li>Other</li> </ul>	
Biliary decompression procedure 2	
28.1 Which procedure was performed?   o ERCP  o PTC	
28.2 Was this procedure in-patient or out-patient?   o In-patient  o 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/1.73m <sup>2</sup>	
28.6 Was the decompression performed in the circumstance of cholangitis?  Yes  No	
28.7 Were peri-procedural IV-fluids given?	
28.8 Were peri-procedural antibiotics given? (within 48h around procedure)	
<ul> <li>Yes, prophylaxis</li> <li>Yes, therapeutic</li> <li>No</li> </ul>	
28.9 Was nephrotoxic medication paused?	
<ul> <li>Yes</li> <li>No</li> <li>Patient was not on any nephrotoxic medication</li> </ul>	
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.	s
28.10 Was a rectal NSAID prescribed peri-procedurally?	
28.11 Were there any post-intervention complications? (More than one answer possible)	
None Bleeding (requiring transfusion of intervention) Perforation	
Cholangitis Pancreatitis (3x baseline amylasis 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?	
o Yes o No	
28.13 Did the patient die as a result of this complication?	
o Yes o No	
28.14 Was the decompression successful? (as decided by the operator's comments in procedural notes)	
28.15 Was the patient readmitted within 7 days of the procedure? Yes No	$\Box$



28.16 Why was the decompression unsuccessful?

o Unable to cannulate o U	nable to deploy stent	o Other	
Biliary decompression procedure 3			
28.1 Which procedure was performed?	o ERCP	o PTC	
28.2 Was this procedure in-patient or out-patient?	<ul> <li>In-patient</li> </ul>	<ul> <li>Out-patient</li> </ul>	
28.3 Date of procedure 3	(dd-mm-yyyy)		
28.4 What was the last serum bilirubin BEFORE this attem	pt to decompress?	μmol/L	
28.5 What was the last eGFR BEFORE this attempt to deco	ompress?	ml/ <u>min</u> /1.73m <sup>2</sup>	
28.6 Was the decompression performed in the circumstant	nce 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)		
<ul><li>Yes, prophylaxis</li><li>Yes, the</li></ul>	rapeutic	o No	
28.9 Was nephrotoxic medication paused?			
o Yes o No o Patie	nt was not on any nephrot	coxic medication	
Examples: NSAIDS (e.g. ibuprofen); ACEi (lisinopril, perindopril), not an exhaustive list and clinical discretion is required.	Angiotensin Receptor Blockers	s (losartan, valsartan); Note -	this is
28.10 Was a rectal NSAID prescribed peri-procedurally?	Yes	No	
28.11 Were there any post-intervention complications? (	More than one answer pos	sible)	
None Bleeding (requiring transfusion of	intervention)	Perforation	
Cholangitis Pancreatitis (3x baseline amylasis	with abdominal pain)	Pneumothorax	
Acute kidney injury (>1.5x increase in baseline serum crea	atinine)		
28.12 Did one of these complication required surgical, rac	liological or endoscopic int	ervention?	
o Yes o No			
28.13 Did the patient die as a result of this complication?			
o Yes o No			
28.14 Was the decompression successful? (as decided by	the operator's comments	in procedural notes)	
o Yes o No	If <b>Yes →</b> please go to q	uestion	
28.15 Was the patient readmitted within 7 days of the pro	ocedure?	Yes No	
28.16 Why was the decompression unsuccessful?			
o Unable to cannulate o U	nable to deploy stent	o Other	
CLIDGEDY			
SURGERY			
31. Was curative surgery attempted?	Yes No	On the waiting list	
If <b>No</b> or <b>Awaiting</b> → please go to question		,	
32. What was the initial planned date of surgery?		nm-yyyy)	
33. Did surgery happen on the initial planned date?	Yes No		
If <b>Yes</b> → please go to question	2		
34. If surgery was initially postponed, what was the reaso			
	lity / institutional factors	o Other	
35. What was the actual date of surgery?	(dd-n	nm-yyyy)	
36. What operation was performed?			
Pancreaticoduodenectomy (PPPD / Whipple)	Hepatectomy +excision	on of extrahepatic	
Distal pancreatectomy	biliary tree		
Total pancreatectomy	Curative procedure a	bandoned	

## CONFIDENTIAL

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Subtotal pancreatectomy	Othe	er			
Central pancreatectomy					
If answered Curative procedure aband	·	ion, otherwise	go to		
37. If abandoned, what operation was	· —				
	· · · · · · · · · · · · · · · · · · ·	en and close	Other		
38. Why was the procedure abandone	7				
Metastatic disease	Locally advanced	Other			
39. Was a vascular resection performe	ed? Yes	No			
PATHOLOGY					
40. What was the pathological type of	malignancy? (Histological co	nfirmation is re	quired)		
Pancreatic adenocarcinoma	Neuroendocrine tumour				
Ampullary adenocarcinoma	Intraductal papillary muc	cinous neoplasm	۱ 📄		
Cholangiocarcinoma	Duodenal	Other	<u></u>		
42.1 Tumour T0	Tis T1	T2	T3	T4	
42.2 Nodes N0	N1				
42.3 Metastasis M0	M1				
ADDITIONAL & SUPPORTIVE CARE					
			Voc	No	
43. Does the patient have unresectable	e disease?		Yes	No No	
43. Does the patient have unresectabl 44. Has the patient been seen by a Clin	e disease? nical Nurse Specialist (CNS)?	reon)	Yes	No	
<ul><li>43. Does the patient have unresectable</li><li>44. Has the patient been seen by a Cline</li><li>45. Have pancreatic enzyme supplementation</li></ul>	e disease? nical Nurse Specialist (CNS)? ents been prescribed? (e.g. Ci	•	Yes Yes	No No	
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