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Performance
and Improvement

NATIONAL OPTIMAL PATHWAY FOR PANCREATIC CANCER: 2nd EDITION (2025)

Point of Suspicion to First Definitive Treatment in Adults (aged 16 and over)

Date of Issue: July 2025	
Date of Review: July 2027	
Owner: HPB Cancer Site Group	

FOREWORD

The NHS Wales National Optimal Pathways (NOPs) have been developed as part of the Suspected Cancer Pathway (SCP) programme of work. They aim to establish consistent generic and site-specific pathways that describe all routes of entry onto the pathway from the point of suspicion (PoS) of cancer. They describe good practice diagnostic and treatment pathways. The diagnostic pathway, including staging, should be performed within 28 days from PoS and definitive treatment commenced within 21 days from date of Decision to Treat (DTT).

However, recognising the impact on survival associated with rapid access to surgical treatment in operable pancreatic cancer, this pathway aims to commence a patient's definitive treatment in less than 28 days from the point of suspicion, which is earlier than the current cancer waiting time of 62 days. Expediting patients through the pathway in a timely manner is essential given the rapid progression of disease. The pathways also describe where patients should receive consistent information and support, tailored to meet their needs.

The NOPs aim to provide a platform to standardise care, reduce unwarranted variation and drive improvement whilst increasing quality across each of the cancer pathways in order to:

- meet the SCP cancer waiting time of 62 days for patients presenting with a suspicion of cancer,
- improve cancer patient experience, and,
- improve cancer patient outcomes throughout Wales to that comparable with the best outcomes in Europe.

The Pancreatic NOP is designed to help pancreatic cancer service providers and their commissioners see the basic structure of an effective and efficient pancreatic cancer pathway. In essence, this optimal pathway is about ensuring that each stage of the pathway happens quickly, that communications with patients are effective and that the entire team works in a coordinated but flexible way, focusing always on the patient's journey. It is recognised that the introduction of the National Optimal Pathway for Pancreatic Cancer may present challenges for the pancreatic multidisciplinary teams. However, introducing a nationally agreed, clinically endorsed pathway will support service improvement. They will also provide clarity and consistency for primary care around the referral process into secondary care, including access to diagnostics, to ensure the patients move through the system in a timely manner.

GROUP CONSULTATION

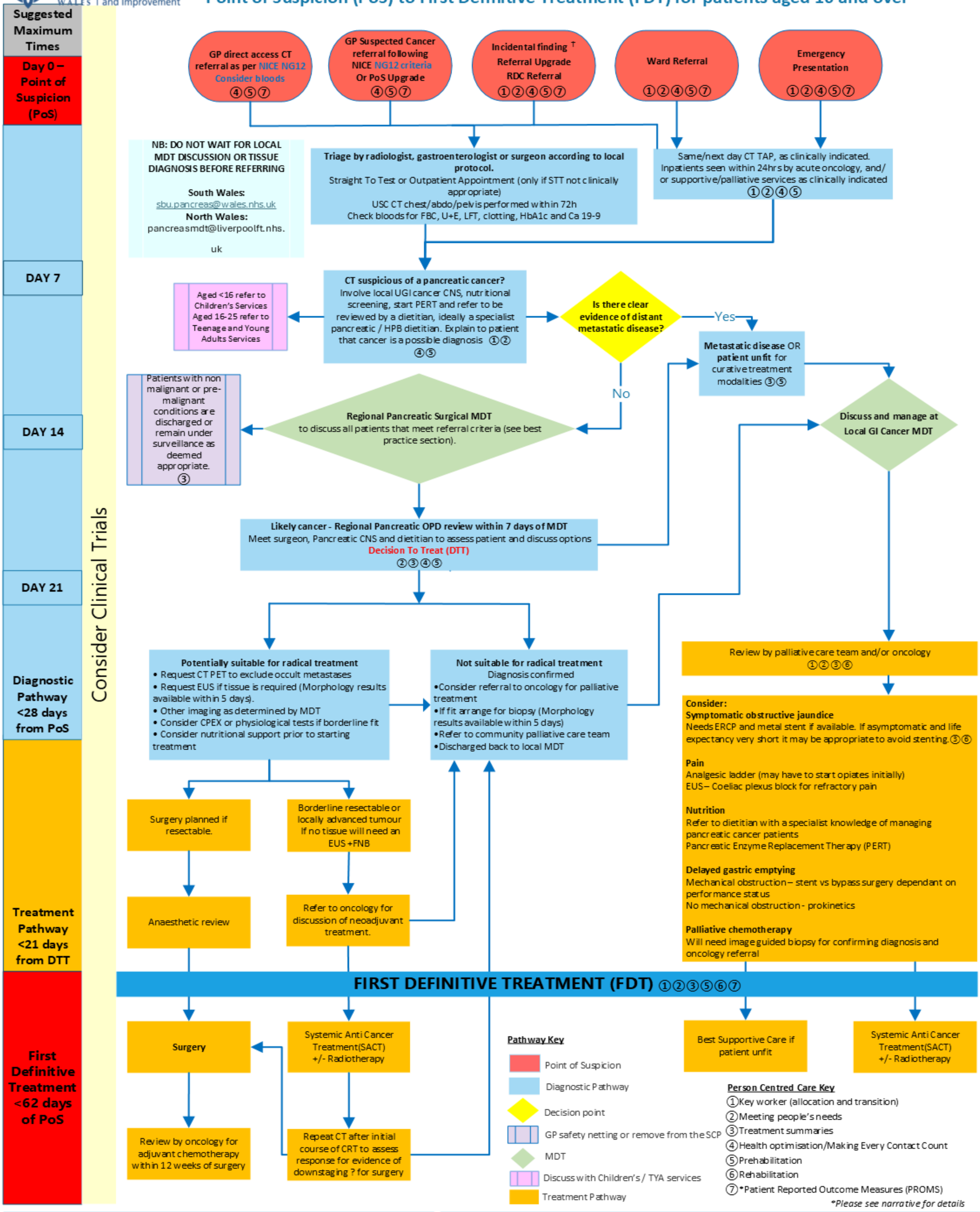
The HPB Cancer Site Group (CSG) is led by Mr. Nagappan Kumar, Consultant Surgeon. The pancreatic pathways work has been led by Mr Guy Shingler, Hepato-Pancreato-Biliary and Laparoscopic Consultant Surgeon. The group includes representation from the full range of professions involved in delivering cancer services. They were all able to contribute and comment on the development of the optimal pathway during a range of pathway workshops, CSG meetings and educational days, commenced in September 2019. An early draft was sent to the Pancreatic Multidisciplinary Teams (MDTs), Health Boards and Velindre NHS Trust in October 2019. Separate workshops were also held with the Clinical Nurse Specialist (CNS) and Allied Health Professional (AHP) members to embed the Rehabilitation and Person-Centred Care (PCC) into the pathway, ensuring all patient's needs are assessed and met in a timely manner. Wider consultation was sought in December 2019 from NHS Wales's stakeholders, including National Imaging and Pathology Networks and the Third sector; 21 responses were received, and these were all carefully considered during the revision process, prior to a final version being issued in January 2020.

This second edition (2025) of the NOP reflects recent changes to practice with the more widespread use of neoadjuvant chemotherapy for borderline disease. The increasing importance of prehabilitation, dietetics input and early use of pancreatic enzymes to improve the proportion of patients who can receive radical treatment is emphasised. Finally, the pathway hopes to improve outcomes for the majority of patients who cannot have radical treatment with the aim to increase access to good standards of palliative care. The pathway for patients who cannot have radical treatment was further discussed in January 2024 among all the stakeholders to ensure optimal care of these patients.

Mr Guy Shingler (Pancreatic Lead Clinician for Pathways)

Mr. Nagappan Kumar (HPB Clinical Lead)

National Optimal Cancer Pathway for suspected and confirmed Pancreatic cancer: Point of Suspicion (PoS) to First Definitive Treatment (FDT) for patients aged 16 and over



Suggested Maximum Times

Day 0 – Point of Suspicion (PoS)

DAY 7

DAY 14

DAY 21

Diagnostic Pathway <28 days from PoS

Treatment Pathway <21 days from DTT

First Definitive Treatment <62 days of PoS

Consider Clinical Trials

GP direct access CT referral as per NICE NG12 Consider bloods ④⑤⑦

GP Suspected Cancer referral following NICE NG12 criteria Or PoS Upgrade ④⑤⑦

Incidental finding † Referral Upgrade RDC Referral ①②④⑤⑦

Ward Referral ①②④⑤⑦

Emergency Presentation ①②④⑤⑦

NB: DO NOT WAIT FOR LOCAL MDT DISCUSSION OR TISSUE DIAGNOSIS BEFORE REFERRING

South Wales: sbu.pancreas@wales.nhs.uk
North Wales: pancreasmdt@liverpoolft.nhs.uk

Triage by radiologist, gastroenterologist or surgeon according to local protocol.
Straight To Test or Outpatient Appointment (only if STT not clinically appropriate)
USC CT chest/abdo/pelvis performed within 72h
Check bloods for FBC, U+E, LFT, clotting, HbA1c and Ca 19-9

Same/next day CT TAP, as clinically indicated. Inpatients seen within 24hrs by acute oncology, and/ or supportive/palliative services as clinically indicated ①②④⑤

Aged <16 refer to Children's Services
Aged 16-25 refer to Teenage and Young Adults Services

CT suspicious of a pancreatic cancer?
Involve local UGI cancer CNS, nutritional screening, start PERT and refer to be reviewed by a dietitian, ideally a specialist pancreatic / HPB dietitian. Explain to patient that cancer is a possible diagnosis ①② ④⑤

Is there clear evidence of distant metastatic disease?

Yes

No

Metastatic disease OR **patient unfit** for curative treatment modalities ③⑤

Patients with non malignant or pre-malignant conditions are discharged or remain under surveillance as deemed appropriate. ③

Regional Pancreatic Surgical MDT
to discuss all patients that meet referral criteria (see best practice section).

Discuss and manage at Local GI Cancer MDT

Likely cancer - Regional Pancreatic OPD review within 7 days of MDT
Meet surgeon, Pancreatic CNS and dietitian to assess patient and discuss options
Decision To Treat (DTT)
②③④⑤

Potentially suitable for radical treatment
- Request CT PET to exclude occult metastases
- Request EUS if tissue is required (Morphology results available within 5 days).
- Other imaging as determined by MDT
- Consider CPEX or physiological tests if borderline fit
- Consider nutritional support prior to starting treatment

Not suitable for radical treatment
Diagnosis confirmed
- Consider referral to oncology for palliative treatment
- If fit arrange for biopsy (Morphology results available within 5 days)
- Refer to community palliative care team
- Discharged back to local MDT

Review by palliative care team and/or oncology ①②③⑥

Consider:
Symptomatic obstructive jaundice
Needs ERCP and metal stent if available. If asymptomatic and life expectancy very short it may be appropriate to avoid stenting. ③⑥

Pain
Analgesic ladder (may have to start opiates initially)
EUS – Coeliac plexus block for refractory pain

Nutrition
Refer to dietitian with a specialist knowledge of managing pancreatic cancer patients
Pancreatic Enzyme Replacement Therapy (PERT)

Delayed gastric emptying
Mechanical obstruction – stent vs bypass surgery dependant on performance status
No mechanical obstruction - prokinetics

Palliative chemotherapy
Will need image guided biopsy for confirming diagnosis and oncology referral

Surgery planned if resectable.

Borderline resectable or locally advanced tumour If no tissue will need an EUS +FNB

Anaesthetic review

Refer to oncology for discussion of neoadjuvant treatment.

FIRST DEFINITIVE TREATMENT (FDT) ①②③⑤⑥⑦

Surgery

Systemic Anti Cancer Treatment(SACT) +/- Radiotherapy

Review by oncology for adjuvant chemotherapy within 12 weeks of surgery

Repeat CT after initial course of CRT to assess response for evidence of downstaging ? for surgery

Best Supportive Care if patient unfit

Systemic Anti Cancer Treatment(SACT) +/- Radiotherapy

Pathway Key

🟥 Point of Suspicion
🟦 Diagnostic Pathway
◆ Decision point
▥ GP safety netting or remove from the SCP
◆ MDT
▥ Discuss with Children's / TYA services
🟧 Treatment Pathway

Person Centred Care Key

①Key worker (allocation and transition)
②Meeting people's needs
③Treatment summaries
④Health optimisation/Making Every Contact Count
⑤Prehabilitation
⑥Rehabilitation
⑦*Patient Reported Outcome Measures (PROMS)

**Please see narrative for details*

Regional Pancreatic MDT Referrals
- Refer to Regional Pancreatic MDT to decide on operability and consideration for trials.
- Vascular involvement is not a barrier to referral.
- **Do not delay** referral for local MDT, ERCP, biopsy or further imaging.
- Please refer by proforma emailed to *SBU.Pancreas@wales.nhs.uk*
- Deadline is **12pm on the Thursday prior** the next week's Tuesday meeting.

Please see Best Practice Guidance section for Regional MDT referral criteria.

Pancreatic Enzyme Replacement Therapy

Prescribe pancreatic enzymes at a starting dose of approximately 75000 units with a main meal, and 25000-50000 units with a snack. If an increase of dose is not effective, consider adding in a proton pump inhibitor to raise the gastric pH.

Creon, Pancrex and Nutrizym are all commonly used and exact dose will depend on preparation. Patients may tolerate one formulation better than another.

BIOMARKER TESTING

Dihydropyridimine dehydrogenase (DPYD) testing on a blood sample via the All Wales Medical Genomics Service (AWMGS) is indicated prior to commencing 5-FU/capecitabine chemotherapy. Test request forms are available via AWMGS and should be directed to the pathology laboratory housing the tissue specimen to be tested; request should not be directly sent to AWMGS.

BEST PRACTICE GUIDANCE

Vetting & Triage	It is recommended that the triage of referrals is undertaken using an electronic system (e.g., Welsh Patient Referral Service) to improve the timeliness, traceability, and governance of pathways. Referrals received as suspected cancer (USC) should be prioritised within 1 day and urgent / routine referrals within 3 days due to the potential need for upgrade to suspected cancer (pathway entry date: date referral originally made by primary care).
Investigations	A good quality contrast enhanced CT with portal venous phases is the mainstay of investigation for patients who have a suspected pancreatic cancer. MRI, Ultrasound (US) and Endoscopic Ultrasound (EUS) and CT-PET are useful diagnostic adjuncts but are not generally used to decide operability. Where practical, reporting radiologists should consider using the PACT-UK standardised reporting template to produce reports as it should help to produce more consistent reports – to improve compatibility with ongoing trials and to improve patient care.
Tissue confirmation	Lack of a biopsy confirming Pancreatic Ductal AdenoCarcinoma (PDAC) should not delay a referral to the regional MDT as surgery is frequently performed without tissue confirmation. In the case of patients who require neoadjuvant or palliative systemic anticancer treatment, tissue is generally considered mandatory prior to starting treatment, though this remains at the discretion of the treating oncologist. Should repeated attempts at sampling fail then it is acceptable to treat without tissue confirmation on MDT recommendation providing the patient is adequately consented of the risks. EUS/ERCP appointments to retrieve tissue confirmation should be booked as early as possible and undertaken in a timely manner to ensure fast diagnosis for individuals receiving SACT.
Regional MDT referral criteria	The following set out the criteria for referral to the regional MDT: -Pancreatic lesion (mass or cyst) -Deranged LFTs in absence of stones +/- mass/cyst -Dilated pancreatic duct +/- common bile duct dilation -The MDT will also discuss referrals with normal CT but raised Ca 19-9 or diagnosis of genetic predisposition to pancreatic cancer (PRSS-1, CDKN2A, SPINK etc.)
Enhanced communication	To ensure that local MDTs are supported to make informed decisions about the treatment and care of palliative patients, communication between the specialist regional MDT and local MDT is recommended.

between specialist and local MDTs	Effective communication channels should be in place between specialist and all local MDTs to ensure cohesive, coherent and collaborative care is offered to all patients; there should be a designated pathway coordinator.
Accelerated Imaging	It is recommended that following suspected malignant findings on imaging such as US or MRI, patients should have a staging CT thorax, abdomen, and pelvis (CT TAP) on the same or next day. These scans should be reported within 2 days and the patient referred to the appropriate MDT.
Key worker role	Patients should be assigned a named key worker who will be a clinical nurse specialist who works in partnership with the local or regional MDT to smooth their progress along the diagnostic and treatment pathways. Patients will initially be assigned to their local Upper GI CNS. Patients reviewed in the regional Pancreatic clinic will have access to the Pancreatic Cancer CNS team based at Morriston for the duration of their treatment.
Medical Optimisation	It is recommended that if diagnostic investigations (endoscopy or radiology) identify a suspected cancer, that teams give thought to patient medical fitness optimisation to run concurrently with pathological staging investigation. This could include consideration of the need for respiratory or cardiology (e.g., echocardiogram) investigation as well as diabetic and anaemia management. Patients should undergo an objective assessment of pre-treatment risk to help inform peri-operative care requirements. They should also have access to peri-operative medical optimisation resources and such as nutritional support, smoking cessation advice, exercise physical activity, and well-being support as well as smoking cessation advice and alcohol support services prehabilitation and intravenous iron.
Nutrition, PERT and PEI	Patients with a suspected diagnosis of pancreatic cancer should be assessed for weight loss and considered for referral to dietetics. Patients should be commenced on Pancreatic Enzyme Replacement Therapy (PERT) irrespective of whether they are symptomatic of Pancreatic Enzyme Insufficiency (PEI). PERT is safe and generally well tolerated. Patients with pancreas cancer will develop PEI over time either as a result of disease progression or from treatment and starting early when they feel well keeps them fit for treatment and can improve survival. NICE NG85 1.6.1-2 recommends that PERT should be offered to all patients with pancreatic cancer before and after resection, as well as to those not able to undergo resection. Work is currently underway to ensure that PERT is available on the formulary so that it can be prescribed by all levels of health professional with prescriber privileges in every Health Board and Trust. An example starting dose would be 75000 units of Creon with a main meal and 25-50000 units with a snack. Other pancreatin preparations such as Nutrizym or Pancrex are equally acceptable at similar doses.
Biliary drainage	Biliary drainage is indicated in patients with symptomatic jaundice and an obstructed bile duct. It is not always needed in palliative patients who are not symptomatic (itching etc) who have a very poor performance status and short life expectancy (weeks) as complications of an invasive drainage procedure may do significant harm at the end of a patient’s life if they occur. Jaundice may also occur for other reasons without biliary obstruction, such as liver failure secondary to metastases and it is important to differentiate these.

<table>
<tr><td></td><td>ERCP is generally the first line procedure for achieving biliary drainage, and the aim should be to place a metal stent and obtain brushings. Whether the patient is operable or not should not affect what type of stent is placed, though it is helpful if the proximal end of the stent can sit below the insertion of the cystic duct to reduce the risk of cholecystitis. EUS guided techniques using a lumen apposing metal stent are also acceptable. Percutaneous transhepatic cholangiogram guided techniques should be reserved for cases when ERCP/EUS have failed as the risk of complications is higher.</td></tr>
<tr><td>Fast track surgery</td><td>Very fit patients with obstructive jaundice will be considered for fast-track surgery without biliary stenting at the discretion of the Pancreatic MDT. This approach has been shown to reduce post operative complications but is not suitable for all patients and depends on availability.

Local MDTs must not wait for local discussion or tissue diagnosis before referral. In order to refer, use the below email addresses and forms based on your location:

<table>
<tr><td>Location</td><td>Contact</td><td>Form link</td></tr>
<tr><td>South Wales</td><td>sbu.pancreas@wales.nhs.uk</td><td>X</td></tr>
<tr><td>North Wales</td><td>X</td><td>X</td></tr>
<tr><td>Powys</td><td>X</td><td>X</td></tr>
</table></td></tr>
<tr><td>Abnormal straight to test radiology results</td><td>These should be acted on rapidly by the requestor who should arrange review of the patient locally within a week to explain the potential diagnosis and refer them on to the relevant MDT. This meeting provides an opportunity for assessment of nutritional status, commencing PERT as necessary and arranging any further tests that may be necessary.</td></tr>
<tr><td>Preservation of tissue for genomics</td><td>It is recommended that the preservation of tissue for genomic testing is taken into account when preparing the initial biopsy sample. Optimal fixation time for genomics requires the specimen not be in formalin for more than 24 hours. Cutting sections up front, (to reduce waste at the microtome) and/or splitting the material over more than one block may also reduce the amount of waste at the microtome (as well as speeding up subsequent requests). Each Health Board and Trust can identify their own practice for this that is suited to local arrangements.</td></tr>
<tr><td>Dihydropyridimine dehydrogenase (DPYD) testing</td><td>People with low DPD enzyme levels can have serious side effects from capecitabine and 5-fluorouracil (5-FU) chemotherapy treatments which are both used for pancreatic cancer treatment. Prior to starting chemotherapy this enzyme level should be checked, but the result can take several weeks to become available. To reduce the time that a patient waits to start chemotherapy, could the referring clinician please send a blood sample for DPYD testing when the decision to refer for chemotherapy is made. This test is requested via the genetics service and requires a special genetic testing form.</td></tr>
<tr><td>Testing for and actively treating diabetes</td><td>Patients found to have a new diagnosis of diabetes should have their blood glucose levels managed aggressively. Due to loss of functioning pancreatic tissue, patients will often need insulin and may require input from secondary care diabetes services. High glucose levels can delay both diagnostic tests such as PET and treatments such as chemotherapy and surgery.</td></tr>
</table>

DEFINITIONS

Below definitions are applicable to all National Optimal Pathways.

Decision to Treat	The DATE on which a **Decision To Treat** is made. For the cancer data sets, the **DECISION TO TREAT** DATE is the DATE that the consultation between the PATIENT and the clinician took place and a Planned Cancer Treatment was agreed. Source: NHS Data Model and Dictionary (datadictionary.nhs.uk)
Direct to Test	GPs have direct access to diagnostic endoscopy, ultrasound, MRI, X-ray and CT for people with suspected cancer. Source: National Institute for Health and Care Excellence, Quality Standard 2016 (QS 124)
First Definitive Treatment	**First Definitive Treatment** is the **first** CLINICAL INTERVENTION intended to manage a PATIENT's disease, condition or injury and avoid further CLINICAL INTERVENTIONS. What constitutes **First Definitive Treatment** is a matter of clinical judgement in consultation with others, where appropriate, including the PATIENT. Source: NHS Data Model and Dictionary (datadictionary.nhs.uk)
Next Generation Sequencing (NGS)	The advent of next generation sequencing (NGS) technology has revolutionised the scale at which genetic testing can be performed, enabling the analysis of many more genes within the same assay. This allows multiple variants (mutations) to be detected per sample. Large gene panel tests (>500 genes) for cancer testing are rapidly being adopted in the UK. Source: Genome UK: the future of healthcare 2020 AWMGS - Cymru Service for Genomic Oncology Diagnoses (CYSGODI) (medicalgenomicswales.co.uk)
Safety Netting	"Safety netting is a management strategy of patients, tests and referrals used in the context of diagnostic uncertainty in healthcare. It aims to ensure patients are monitored until signs and symptoms are explained or resolved." Source: Royal College of General Practitioners (RCGP) - Home
Straight to Test	"Following clear referral criteria into secondary care (usually NICE guidance) the secondary care clinician (defined as per local protocol) will arrange a diagnostic procedure as the first episode of care in place of an outpatient episode. The clinician will retain clinical responsibility for the result including acting on the result." Source: Delivering Cancer Waiting Times NHSE
Teenagers and Young Adults (TYA) Service	Young people (aged 16-24 years) with cancer have their diagnosis treatment and support agreed and delivered by a cancer-site specific multidisciplinary team and a teenage and young adult multidisciplinary team. Source: National Institute for Health and Care Excellence (NICE), 2014. Cancer services for children and young people (QS55)

CLINICAL EVIDENCE

Point of Suspicion/ Referral	The point of suspicion is when a clinician refers a patient or requests a test concerned that a patient may have cancer. Pathway start dates are defined in the following guidance: Single Suspected Cancer Pathway Definitions (December 2018) Additional information: Cancer Risk Assessment Tool (RAT) Q Cancer Risk Assessment Tool
Diagnosis and Management	National Institute for Health and Care Excellence (NICE) NG85 Pancreatic Cancer in Adults: Diagnosis and Management Pancreatic Cancer UK as a charity provide a wide range of training for health professionals to improve awareness and expertise about pancreatic cancer, further guidance can be found via: Learning and development for health professionals - Pancreatic Cancer UK.

PERSON CENTRED CARE

Key Worker	QS 14: Patients are made aware of who to contact, how to contact them and when to make contact about their ongoing healthcare needs. National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services A cancer key worker is *"a person who, with the patient's consent and agreement, takes a key role in coordinating the patient's care and promoting continuity, ensuring the patient knows who to access for information and advice."* 1. All cancer patients must have an allocated key worker. 2. Allocation / Review of key worker to take place at key time points including: a. Around the time of diagnosis **please note: allocation of key worker **may** occur earlier than time of diagnosis, if there is a very high level of suspicion of cancer e.g. evidence obtained via pathology, radiology, endoscopy.* b. Commencement of treatment Key workers for cancer patients (Welsh Health Circular /2014/001) GOV.WALES Cancer Improvement Plan for Wales
Meeting People's Needs	QS 4: Patients have opportunities to discuss their health beliefs, concerns, and preferences to inform their individualised care. QS 10: Patients have their physical and psychological needs regularly assessed and addressed, including nutrition, hydration, pain relief, personal hygiene, and anxiety. National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services

	Assessment and discussion of patients’ needs for physical, psychological, social, spiritual and financial support should be undertaken at key points including: • Around diagnosis *_please note: undertaking a Holistic Needs Assessment **may** occur earlier than time of diagnosis, if there is a very high level of suspicion of cancer e.g. evidence obtained via pathology, radiology, endoscopy; and it is supported by professional judgement._ • At commencement, during, and at the end of treatment. National Institute for Clinical Excellence (NICE, 2004) CSG4 Improving Supportive & Palliative care for adults with cancer Patients should be signposted to third sector support information. Ideally Holistic Needs Assessments should be undertaken electronically. Cancer Improvement Plan for Wales The Macmillan eHNA is *one* tool which is both valid and reliable. Snowden A & Fleming M (2015) Validation of the electronic HNA. Where appropriate, the impact of the cancer and its treatment on future fertility should be discussed with the cancer team at the earliest opportunity. The eligibility criteria for treatment are set out in the WHSSC Specialist Fertility Commissioning Policy, CP38 (link below). Opportunity should be provided to explore any individual concerns and address any unmet needs and early speciality referral should also be offered. whssc.nhs.wales/commissioning/whssc-policies/fertility/specialist-fertility-services-commissioning-policy-cp38-feb-2020/
Health Optimisation / MECC	QS 9: Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their coexisting conditions. National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services Health Optimisation refers to a proactive approach to supporting people who present to NHS services with concurrent comorbid health conditions (e.g. anaemia, diabetes), or health risk behaviours (e.g. smoking, physical inactivity). Welsh Government (2024) A Healthier Wales Welsh Government (2015) Wellbeing of Future Generations Act. Making Every Contact Count (MECC) is a behaviour change approach that helps health and social care professionals to help people to improve their health and wellbeing through prevention and early intervention. MECC // Public Health Network :: Home ***Lifestyle advice / resources are available*** *from* Making Every Contact Count (MECC) _*Please note: Whilst addressing concurrent comorbidities and health risk behaviours is the responsibility of **all** health and social care professionals, at **every** contact throughout the pathway; earliest possible intervention **may** impact on cancer treatment choices / outcomes (especially in respect to tobacco smoking)._ National Institute for Clinical Excellence (NICE, 2021) NICE Guidance Tobacco: preventing uptake, promoting quitting and treating dependence

Prehabilitation	Prehabilitation is a needs-based multi-modal intervention, before and during cancer treatment, to optimise physical, nutritional and psychological status, enhance readiness for and tolerance of treatments and improve recovery and/or quality of life. Prehabilitation involves screening before needs-based assessment, enabling individualised prescription of exercise, nutrition and psychological interventions supported by behaviour change techniques. Patients should have the opportunity to take part in evidence-based education and rehabilitative activities, including self-management programmes, *where available*, that promote their ability to manage their own health if appropriate. National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services Welsh Government (2018) A Healthier Wales. Welsh Government (2015) Wellbeing of Future Generations Act. The Quality Statement for Cancer.
Rehabilitation	All patients will have their needs for rehabilitation services assessed, with referral to an appropriate level of rehabilitative support, throughout the patient pathway including timely access to allied health professional to meet individual holistic patient needs and goals. **Please note: not **all** patients will require specialist cancer rehabilitation services. Referral into non-cancer rehabilitation, self-management, and fitness services **may** be suitable to meet some patients' needs.* National Institute for Health and Care Excellence (NICE) CSG4 (2004) resources for improving supportive and palliative care for adults with cancer
Patient Reported Outcome Measures (PROMs) / Patient Reported Experience Measures (PREMs)	Patient Reported Outcome Measures (PROMs) are questionnaires that patients are asked to complete **before** and **after** treatment to assess the impact on health and wellbeing. ***Some*** of the Cancer Site Groups (CSGs) have been working with the International Collaboration for Health Outcome Measurement (ICHOM), National Value in Health Team, Home - Value in Health and other partners, to pilot tools and data capture methods, which will inform a consistent approach to PROMS for cancer. The Quality Statement for Cancer **Please note: there are outstanding questions relating to tool selection, data capture intervals, data capture methods and data analysis / reporting which **may** prevent the implementation of PROMS & PREMS across all pathways at this time. PROMS & PREMS have been included in the pathways, in recognition of this work, and will be updated pending further advice from the CSGs.* Patient Reported Experience Measures (PREMs) are questionnaires that patients are asked to complete at **any time** during their pathway to help professionals to understand their experience of NHS services. This information is crucial to understanding the value of healthcare as perceived by patients. Welsh Government (2024/25) People's experience framework **Please Note: Whilst it is good practice to collect PREMS throughout the pathway, there is no current standard for cancer PREMS in Wales; further advice regarding this will be sought via the CSGs in due course.*

Communication	Clinicians must ensure patients are kept up to date about their care pathway and are supported to make individualised choices about their treatment. Clinicians should consider the value of interventions and discuss with the patient the likely outcome of treatment options. Clinicians in secondary and tertiary care must ensure that all decisions relating to a patient's care or treatment are communicated to the patient and their primary care clinician in a timely manner and within 24 hours of diagnosis. Clinicians must ensure that the clinical intention of any intervention such as tests or treatment is clear to patients, and whether it is just a stage of the agreed pathway or considered start of first definitive treatment and as such ends the pathway. Clinicians must make contemporaneous records of discussions and decisions and include reasons for deviations from recommended clinical practice in the patient's clinical record. Decisions should be made in a timely manner, and any onward referrals be completed promptly, according to local/national guidelines and optimal pathways and include adequate information to allow the receiving clinician to initiate appropriate interventions with the minimum of delay. Referrers must ensure that the patient is aware and agrees for a suspected cancer referral to be made. Suspected cancer pathway: guidelines (WHC/2023/025) | GOV.WALES **Treatment Summary** A treatment summary is a tool completed by secondary care professionals after a significant phase of a patient's cancer treatment. A treatment summary describes the patient's cancer diagnosis, prognosis, and aim, types and side effects of any treatment that they have had. It also highlights any signs and symptoms of recurrence that the patient needs to be aware of. It is designed to be shared with the person living with cancer and their GP either electronically or as a paper document, and should use easy to understand, clear and concise language. Additionally, it can be used by the person affected by cancer to help inform other health and social care professionals, employers/occupational health or financial institutions e.g., benefits services or banks, about their cancer care and treatment.
Research	Patients should have the opportunity to take part in research and clinical trials where available. If a patient diagnosed with pancreatic cancer also has a family history of pancreatic cancer, family members can self-refer to the EUROPAC trial for at risk surveillance. People in research | Health Care Research Wales (healthandcareresearchwales.org) EC Trial Finder | ECMC (ecmcnetwork.org.uk)