

Key Notes

Variation in the Pathway from Diagnosis to Treatment – Anna Jewell, Director of Support, Research & Influencing, Pancreatic Cancer UK

- There is variation in survival between the UK and rest of the world, with five-year survival in other nations almost two times higher than the UK. One-year survival for pancreatic cancer ranges from 21.3% to 29.1% and five-year survival ranges from 4.8% to 10.6% across Cancer Alliances in England.
- The median pancreatic cancer pathway length from referral to first treatment for pancreatic cancer is 36 days, with 12 days between urgent cancer referral and diagnosis and 24 days between diagnosis and first treatment
- People who are diagnosed at an early stage have a slower median pathway length between referral and first treatment compared to people diagnosed with metastatic pancreatic cancer (45 days vs 33 days)
- There is a large range in the median pancreatic cancer pathway length between cancer alliances. The Cancer Alliances with the longest median pathway length was Kent and Medway and South East London, while the shortest median pathway length was Wessex
- There is a strong correlation between younger age and longer median pathway length, particularly for the time between MDT and first treatment (49 days)
- Emergency presentation has the quickest pathway length – 18 days between referral and first treatment
- An optimal pathway should cover the whole spectrum of care - from presentation of symptoms to diagnosis, access to best treatment and supportive care for those living with and beyond pancreatic cancer. It should be a holistic approach to ensure that patients access supportive care to ensure management of symptoms and psychological support is considered straight from diagnosis
- Key pancreatic cancer optimal care pathway features include Rapid Diagnostic Centres for vague and non-specific symptoms, Rapid access jaundice clinic and one stop clinics, bridging clinics, dedicated pancreatic cancer clinics for inoperable patients and prehabilitation before treatment.

Interview: Personal Experience of Pancreatic Cancer and the Pathway – Claire Ray and Sarah Bell, Head of Services, Pancreatic Cancer UK

Claire's mum was diagnosed with metastatic pancreatic cancer in September 2019 aged 65. Claire described how her mum started to get symptoms in January 2019 and attended the GP where she was referred for an ultrasound and then a private CT scan. It took 6 – 8 weeks to find out it was cancer, at which point her mum turned jaundice rapidly. Claire's mum had multiple

delayed and unsuccessful stents which resulted in pancreatitis. As a result Claire's mum declined quickly during this period.

The communication was difficult, with limited access to information and a specialist nurse, who had limited time or capacity for updates so the family struggled to get a full diagnosis. Only at this point was Claire's mum given a full pancreatic cancer diagnosis and the diagnosis was given on a public ward.

It was a further three months between diagnosis to starting treatment, at which point they were linked into a local palliative care team and care became more joined up and they had a more positive experience. Claire's mum had 2 cycles of gemcitabine, before the cancer had progression spine, at which point palliative radiotherapy was offered, although this led to paralysis in arms and repeated infections and Claire's mum was moved to a hospice.

Claire described that one change she would make to the pancreatic cancer pathway would be to look at the patient as a whole, as the care her mum received felt very segmented, with departments not talking to each other and discontinuity in care. Claire also highlighted that speed is important.

Claire described that it was difficult to receive any care or support and Claire found that the Pancreatic Cancer UK support line nurses were a very important area of support. Claire's mum was unable to get access to PERT because health professionals kept saying it was not their responsibility to prescribe PERT or saying it wasn't valuable or important. Claire only heard of pancreatic enzymes because of PCUK information and support.

The Latest in the Pathway from Diagnosis to Treatment – Dr Andrew Millar,

Consultant Gastroenterologist and Hepatologist, North Middlesex University Hospital and Joint NCL Cancer Alliance Clinical Lead for Rapid Diagnostic Centres

- The Anderson model of total patient delays shows that there are delays in the patient action (appraisal and self-management, help seeking) and action by diagnosticians in primary care (healthcare professional appraisal, investigations and referrals).
- Patients attend their GP with symptoms on average 3 times and 93% have symptoms in the 2 years prior to diagnosis.
- It is important to diagnose symptomatic pancreatic cancer earlier as progression time from stage T1 to T4 is just over a year and tumour growth is exponential.
- Programmes to improve the referral pathway include Rapid Diagnostic Centres (RDCs), Q score decisions tool, increasing primary care access to diagnostics, RCGP cancer training toolkits and new biomarkers on the horizon,
- RDCs offer avoidance of multiple pathways and multiple GP appointments. The CRUK ACE MDC programme had a 8% conversion rate for cancer, of which 10.6% (n = 25) were pancreatic cancer.

- In North Central London, the MDC had a 6% cancer conversion rate and 16% were pancreatic cancer (April 17 – April 19). The most common reason for referral was weight loss (40%) and abdominal pain (21%). GP gut feeling was also an important factor.
- In the North Central London MDC there was considerable challenge in clinic availability and radiology and endoscopy waiting times in all sites. National RDC specification and resource allocation could help to resolve this and a key learning from Covid-19 is moving to more virtual and agile services with remote consultations and utilising external diagnostic sites.
- In the future, RDCs will improve efficiency of site specific pathways and support research – biomarkers, self-referral tools and population awareness.
- The future will look like RDCs for rapid and earlier diagnosis, biomarkers to triage in primary care, decision support tools to inform public awareness and enable self-referral, national surveillance for pre-malignant lesions and joint care records to improve communication and research.

Improving the MDT Function – Mr Alastair Young, Consultant Pancreaticobiliary Surgeon, St James's University Hospital, Leeds

- The function of the MDT has become more important as patient pathways become more complex.
- At the Leeds Pancreatic and duodenal cancer MDT they have one MDT per week with 35-50 patients discussed over 3 hours. An audit of the pancreatic cancer MDT discussions found that there were 1811 discussions about 1199 patients. 46% of these patients had pancreatic cancer. Of these patients 18% do not survive 30 days after discussion, 38% have metastases at presentation and 14% have resection.
- 69% of patients discussed had not been met by anyone at the MDT and 65% had incomplete referral information available. 13% of patient discussions could not reach a conclusion because of missing data and 43% of patients received no interactive discussion – with case presented and outcomes dictated.
- Using the Kaizen improvement process (model for continuous improvement), improvements have been made to the MDT, including Improved pancreatic cyst protocol to focus discussions on cancer patients, electronic referral forms – to improve data flow and auto-populating the outputs.
- COVID-19 has increased use of virtual MDT but most felt that communication was disadvantaged and decisions were negatively impacted by virtual MDT.
- A study of 7 centres in the UK and Scandinavia found large variation in MDT assessment of resectability and treatment allocation based on the same information.
- Learning from Boston, where outcomes are excellent and have a high throughput of patients, are that Boston MDT have multiple meetings a week, a separate team to manage acute pancreatitis and no acute surgery involvement. In comparison, Leeds have one meeting per week, which can introduce delays.

- Boston also have combined cancer clinics, where patients with borderline operable/LAPC are discussed in clinic with the patient present. Advantages include shared decision making, MDT working and improved communications.
- An ideal pancreatic cancer MDT, should be consistent with high quality decisions that don't delay treatment, it should have all information available and discussions should add value. MDT processes can be continuously improved driven by data and focusing pancreatic clinicians' time on patients with pancreatic cancer.

From the GP Surgery to Treatment – Challenges to Overcome – Mr Thomas

Satyadas, Consultant HPB Surgeon, Manchester University Foundation Trust and HPB Pathway Clinical Director, Greater Manchester Cancer Alliance

- Outcome post surgery have improved but most patients will never have surgery. Prehabilitation is good innovation but is mainly focused on operable patients. Many things are lined up for operable patients, but not for palliative care patients.
- There are different patient experiences in patients with jaundice compared to patients with no jaundice.
- Greater Manchester Cancer Alliance are implementing a 14 day referral to treatment pathway for pancreatic, bile duct and ampullary cancer pathway.
- With the rapid diagnostic centres, patients with jaundice will have access to CT scan within 24 hours. The pathway also includes daily fast track to MDT and care coordinators.
- Pancreatic cancer patients have the second highest suicide risk of all cancers and 50% have depression at diagnosis – more needs to be done. Better psychological support can improve quality of life
- Greater Manchester are supporting implementation of RDCs for HPB, but there is also a need to educate public as well and Gateway C for GP awareness.

Early engagement of local Clinical Nurse Specialists – Ms Anya Adair, Transplant/HPB Consultant Surgeon, Royal Infirmary Edinburgh

- Pancreas collaborative was established in 2019 within the Scottish HPB Network (SHPBN) to reduce variation and standardise care. An audit of care was established with a questionnaire of secondary and tertiary care across all 14 health boards.
- The audit found that there is inconsistent patient referral, investigation and management pathways, variable delays in reporting of staging investigations, and that individual clinician preference can influence referral pathways.
- The audit also found that referral information pre MDT is inconsistent / incomplete, communication of outcome to patients, referring clinicians and general practitioners pre MDT is inconsistent and time to initiation of treatment regularly exceeds 62 days from referral.

ANNUAL SUMMIT 2020

IMPROVING OUTCOMES NOW

Improving the Pathway from Diagnosis to Treatment, 29th Sept 2020, 9 – 11am

Supported by   

- It was also found that there is inconsistent access to a full range of treatments or research trials across Scotland and that specialist nurse time is taken up organising staging investigations/ administering MDTs rather than maximising direct patient contact and there is also variable CNS, community palliative care, dietetic, and psychological support.
- To improve early management, there is a need to avoid delays, streamline the referral process, prevent deterioration of performance status and improve communication between stakeholders. Currently there is no single person taking responsibility for the patient's cancer journey in Scotland.
- The SHPBN national questionnaire also found that hepatocellular carcinoma (HCC) have similar issues across Scotland – with 52.17% not having access to CNS. It was also found that CNS's are key to coordinating the patient journey and helps continuity of care.
- The Key worker/CNS/Navigator role should ensure communication with patient and family, ensure communication between departments and hospitals and ensure the patient pathway is smooth as possible.
- QPI (Quality Performance indicators) provide quality improvement in cancer care across NHS Scotland. A new QPI for 2020 is that patients with HCC should have a keyworker to coordinate care across the patient pathway. A new QPI for 2020 was added for palliative therapy for pancreatic cancer - 'Patients with inoperable pancreatic cancer should be seen by an oncologist to assess suitability for systemic treatment' – target 50% within 6 weeks of initial CT scan.
- SHPBN have set up a Best Supportive Care collaborative to standardise care and reduce variation in Scotland.