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Northern Ireland Pancreatic Cancer audit: measuring the quality of care for patients diagnosed 2019-2020

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Northern Ireland Pancreatic Cancer Audit

Measuring the quality of care for patients diagnosed 2019-2020

ST Hawkins, R Santos, D Johnston, S McCain, D Bennett, HG Coleman

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Contents

Executive Summary and Key Recommendations

This Pancreatic Cancer Audit assesses the diagnosis, treatment, care and support of patients diagnosed with pancreatic cancer in Northern Ireland by comparing with previous audits and national and professional guidelines and identifying where improvements can be made.

540 patients diagnosed during 2019-2020 were investigated, including patients with malignant neuroendocrine tumours (NET) and adenocarcinomas. Where appropriate patients with malignant NETs were excluded from analysis as these are rare malignancies with very different treatment pathways and survival outcomes.

Key findings:

- **86% rise in confirmed pancreatic cancer cases between 2001 and 2020** (152 in 2001 and 283 in 2020).
- The **majority of patients (94%) were symptomatic** at diagnosis.
- The **most common route to diagnosis was via emergency admission**. Patients diagnosed electively were more likely to have localised stage I-III disease.
- **The majority of pancreatic cancer patients present with distant stage IV disease**. Diagnosing pancreatic cancer at an earlier stage has a major impact on prognosis, with 1 year survival of 52% for stage I compared to only 6% for stage IV patients.
- **Almost all patients (99%) were discussed at MDT** before starting treatment.
- A **quarter of patients had suspected liver metastasis** at diagnosis.
- **4 out of 5 patients had a palliative treatment plan**. This **varied by histological type** - the **majority of adenocarcinoma NOS patients were treated with palliative intent (83%)** while the **majority with a malignant neuroendocrine tumour (NETs) were treated with curative intent (56%)**.
- **Curative patients receiving neoadjuvant treatment** and surgery had the **longest median wait time from referral to treatment of 72-79 days.**
- Before the COVID-19 pandemic, pancreatic surgery was centralised at a single site at MIH, Belfast. **After onset of the pandemic in 2020 surgery was spread across three BHSCT sites**, namely MIH, RVH and BCH.
- **Median inpatient stay was 11 days**. Patients **without post-op complications had a median stay of 10 days** while **those with post operative complications had a median stay of 15 days.**
- **36% of curative patients** who underwent neoadjuvant treatment **have their planned surgery after three cycles.**
- An average of 87 patients received oncology treatment in 2019 and 2020, with approximately an additional 45 patients being referred to oncology each year but not receiving treatment.
- The **two main categories of referral for palliative patients were to specialist Hospital and Community Palliative Care Teams (PCTs) (66%) and District Nursing (62.4%)-** District nurses perform a large volume of community palliative care work**.** Approximately 1/5 of patients were referred to social services.
- **Enrolment in clinical trials was low** at 0.9%.

Recommendations:

- Pancreatic cancer services should be **appropriately funded to manage increasing patient numbers.**
- **Primary prevention and health promotion campaigns**, including **reducing obesity, smoking** and **increasing physical activity,** should be continued and developed.
- **Early diagnosis is key.** Health agencies and wider stakeholders (e.g. PHA, DOH) to **increase awareness of pancreatic cancer symptoms** among the public and GPs to **improve earlier diagnosis.**
- Use of a measure such as the Clinical Frailty Score may **support more equitable treatment access across age groups.**
- HPB team to work with radiology and gastroenterology to ensure **more timely access to PET-CT and EUS**, which. will aid quicker referral to 1st treatment and help achieve 62-day targets.
- HPB and radiology teams to ensure **timely access to MRI and laparoscopy for patients with suspected liver metastasis** as per NICE Guidance.
- Clinicians to assess the impact of **prehabilitation** on post-surgical outcomes and inpatient stay.
- HPB clinical cancer team to **facilitate and encourage better access to clinical trials** for pancreatic cancer patients.
- **Personalised and holistic care** should be provided and supported for all pancreatic cancer patients.

Foreword

I am delighted to introduce this audit on the presentation, investigation, treatments, and outcomes for patients in Northern Ireland (NI) diagnosed with pancreatic cancer. This report provides a detailed insight into the diagnosis, care and outcomes for pancreatic cancer patients in 2019 and 2020. The incidence of pancreatic cancer is on the increase in NI (86% rise in cases between 2001 and 2020) and incidence rates in the most economically deprived areas were 38% higher than the NI average. Similarly of concern is that most patients presenting as emergencies had advanced disease (approximately two thirds of pancreatic cancer patients who had an emergency admission were diagnosed with stage IV disease, whereas 50.5% of patients who had an elective admission were diagnosed at an earlier stage I-III).

The pandemic has also had an impact with a reduction in the proportion of patients who received surgery in 2020 (11.7%) compared to 2019 (21%). However, the report also highlights many areas of success including a significant increase in the number of patients presented at a multidisciplinary meeting (13.2% of patients discussed in 2001 compared with 92.6% in 2020). It clearly sets out recommendations for the entire health system to continue to strive to improve diagnosis, treatment options, enhanced palliative care and improved prognosis.

I would like to thank NIPANC for funding this important work through the Northern Ireland Cancer Registry (NICR), which is funded by the Public Health Agency (PHA). I would also like to acknowledge the NICR staff whose work has produced this report; from securing funding to collation and analysis of data to interpretation and presentation of results. The audit team continually linked with clinical teams to facilitate data availability and validation and interpretation of results. We hope this report's findings will be used by a wide range of stakeholders to identify areas of good practice and shared learning as well as areas for improvements which can enhance patient outcomes.

This work confirms the value of undertaking regular audit to monitor changing processes of diagnosis and treatment for cancer patients in NI and highlights that for audits to be effective, they need to be cyclical. We hope this audit can be repeated to examine future implementation relative to recommendations and to monitor post-COVID19 developments.

Crucially, it will also allow benchmarking against other nations such as the new upcoming England/Wales audit report, which is expected soon.

Prof Mark Taylor CStJ DL PhD FRCSI FRCS(Eng) FRCS(Gen Surg)

Consultant Hepatobiliary and Pancreatic Surgeon

April 2023

Acknowledgements

We wish to acknowledge the invaluable contributions of the following HSC staff who helped design the audit: Mr Mark Taylor, Miss Claire Jones, Mrs Alex McAfee (on behalf of Clinical Nurse Specialists), Dr Paul Kelly, Dr Martin Eatock and Dr Richard Turkington. A special word of thanks to Miss Jessica Lockhart, Specialty Registrar in Surgery, who assisted report co-authors Mr Stephen McCain and Miss Dorothy Johnston in collating and verifying surgical data. Miss Johnston provided great support in collecting data on supportive care services, who for many patients is the mainstay of their treatment.

NICR depend on a dedicated team to develop clinical audits and we thank former director, Professor Anna Gavin and IT staff involved in baseline data collation of audit proforma creation. Three of NICR's Cancer Intelligence Officers (CIOs) (Bernadette Anderson, Marsha Magee and Brid Morris-Canter) extracted data from electronic clinical records with great diligence. Audit oversight and data analysis was primarily undertaken by Sinéad Hawkins with additional analysis from Ralph Santos, guidance from NICR Deputy Director, Professor Helen Coleman and drafting input from undergraduate student, Bláithine Donnelly. We also thank the NICR Steering Group and Council who guide our work.

2023 marks a very special occasion for the NICR team, with Mrs Bernadette Anderson's retirement after 25 years of service. Bernadette is widely regarded as the hepato-pancreato-biliary (HPB) cancer registration specialist and was pivotal in previous NICR pancreatic cancer audits (2001, 2007). Bernadette will be sorely missed but can reflect on a fulfilling career focused on developing high quality data and intelligence that has supported healthcare services for cancer patients in Northern Ireland. It is therefore fitting that we dedicate this report to Bernadette, alongside patients, relatives, and individuals affected by pancreatic cancer in Northern Ireland. This work uses data provided by patients and collected by health services as part of their care and support, and we express out thanks to them. We also thank the Public Health Agency who fund NICR.

The work of this audit report was made possible by funding from NIPANC, a relatively new charity which has made hugely positive impacts in raising awareness, supporting individuals affected by pancreatic cancer, and funding research in Northern Ireland. Led by inspirational chairman and pancreatic cancer survivor, Mr Ivan McMinn MBE, we look forward to continuing to work with this pro-active charity in the future.

Damien Bennett

Director, N. Ireland Cancer Registry, April 2023

Background to NI Pancreatic Cancer Audits

The NICR provides official statistics for cancer incidence, prevalence and survival for Northern Ireland (NI) with cancer incidence data from 1993 to 2020. NICR has previously undertaken audits of the quality of cancer care for several cancers which can be accessed at https://www.qub.ac.uk/research-centres/nicr/research-audits/Audits/.

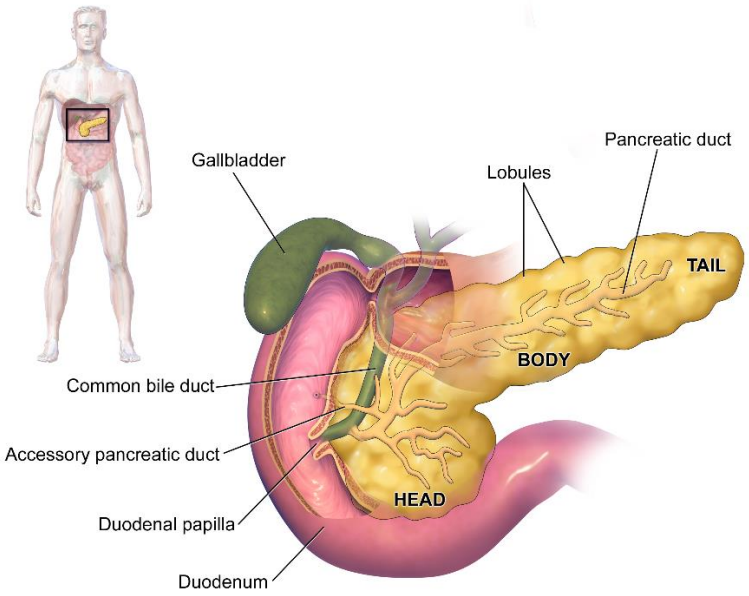
Previous population-based audits for the quality of care for patients with pancreatic cancer in NI have been conducted for patients diagnosed in 2001 and 2007. NICR was awarded funding from the charity NIPANC for a NI-specific pancreatic cancer audit to support delivery and improvement of high quality, clinically effective services designed to improve patient survival and patient-related outcomes.

This audit allows comparison of service delivery with recommended guidelines, with previous NI audits and also with peer regions across Great Britain and countries across the world. It also reports on pancreatic cancer services pre-COVID in 2019 and in 2020, when the COVID-19 pandemic impacted health services in NI. The impact of the COVID-19 pandemic on pathologically diagnosed cancers are published regularly on the NICR website, see: https://www.qub.ac.uk/research-centres/nicr/.

Introduction

The pancreas has three sections: the head, body, and tail. 60-70% of pancreatic cancers are thought to originate in the head of the pancreas (Cancer Research UK, 2023). The pancreas has an exocrine and endocrine function. The exocrine part of the pancreas is a reservoir of digestive enzymes, and the endocrine section is the source of insulin which is vital for carbohydrate metabolism.

Figure 1. Anatomy of the pancreas. (Blausen, 2014)



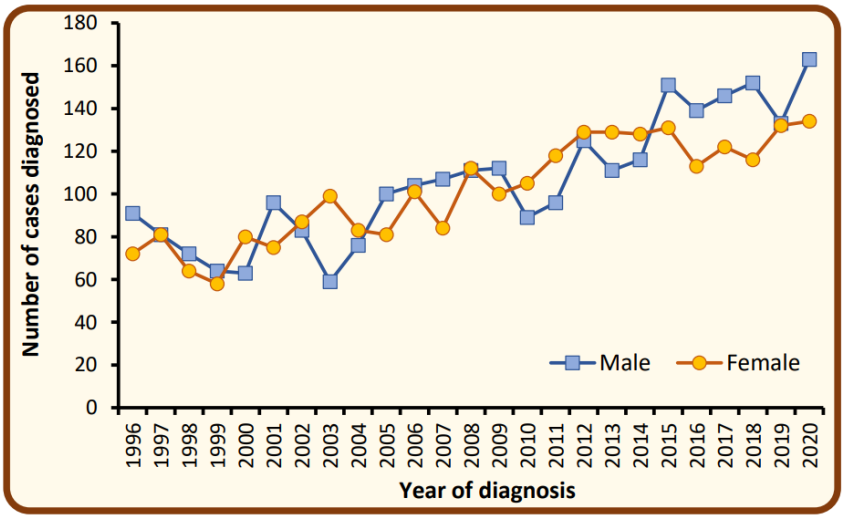
There are two main types of pancreatic cancer tumour types: exocrine ductal adenocarcinoma which makes up 90% of cases and endocrine tumours which account for less than 5% of cases (Hidalgo et al, 2015; Vincent et al, 2011). There are also rarer types of exocrine pancreatic cancers such as cystic tumours, cancer of the acinar cells, pancreatoblastoma (which is mostly found in children), sarcomas of the pancreas and lymphoma (Haerbaele & Esposito, 2019).

Incidence

According to GLOBOCAN 2020 data, pancreatic cancer accounted for 2.6% of all incident cancers and 4.7% of all cancer deaths worldwide (Sung et al, 2021). In 2020 there were 495,773 new diagnoses and 466,003 deaths attributable to pancreatic cancer (Sung et al, 2021). Globally, it has been estimated that pancreatic cancer incidence and mortality rates have increased by 55% and 53%, respectively, over the last 25 years (Lippi & Mattiuzzi, 2020).

In NI between 2016 and 2020 there has been an average of 270 new cases of pancreatic cancer per year and an average of 252 deaths per year in the same time period (NICR, 2023). In NI, the number of people diagnosed with pancreatic cancer has increased from 174 cases in 1993 to 297 in 2020, representing an increase of 71% (Figure 2, NICR, 2023).

Figure 2. Trend in number of pancreatic cancer patients by sex in NI, 1993-2020 (NICR, 2023)



The corresponding age-standardised incidence rates between 2016 and 2020 in NI were 20.1 cases per 100,000 for males and 13.9 cases per 100,000 for females, although this difference was not statistically significant (NICR, 2023).

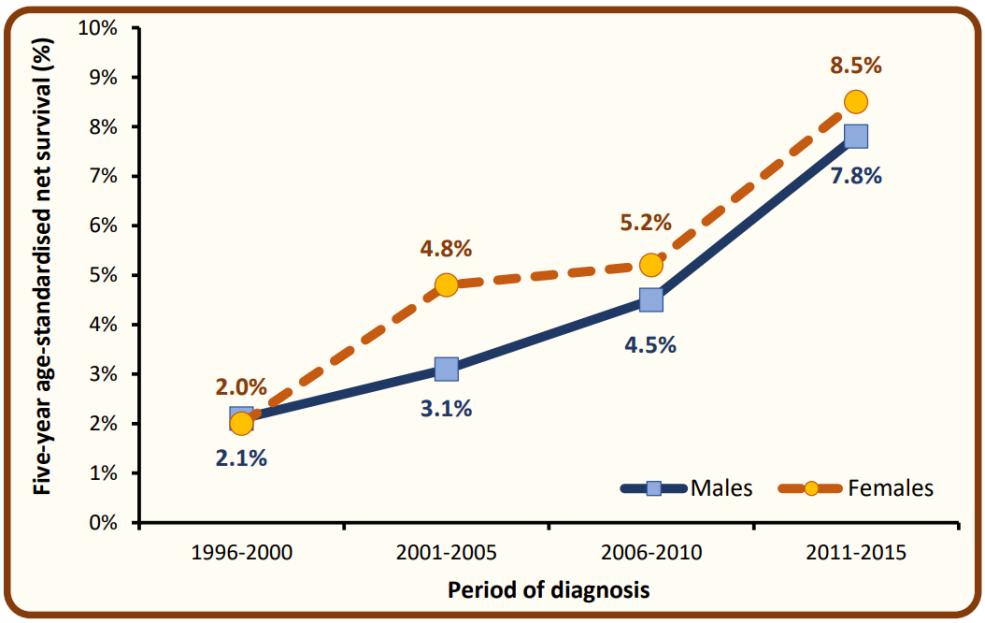
Prevalence

At the end of 2020, there were a total of 341 people living with pancreatic cancer in NI who had been diagnosed in the previous 25 years. Of these, 185 were male and 156 were female. Just over one third of prevalent pancreatic cancer patients (36.4%) had been diagnosed in the previous year (NICR, 2023).

Survival

Survival for pancreatic cancer patients is poor. Patients diagnosed in 2011-2015 and followed up to the end of 2020 had a 5-year age-standardised net survival (ASNS) of 8% (Figure 3, NICR 2023). ASNS measures survival without the effects of deaths from causes unrelated to pancreatic cancer. Survival rates for pancreatic cancer are slowly improving; for patients diagnosed between 1996-2000 the ASNS rate for males was 2.1% which increased to 7.8% by 2011-2015. In females there was also an increase, from 2% in 1996-2000 to 8.5% in 2011-2015 (Figure 3, NICR, 2023).

Figure 3. Trends in age-standardised five-year net survival by sex, for patients diagnosed with pancreatic cancer in NI, 1996-2015 (NICR, 2023)



Between 2012-2015 the majority of pancreatic cancer patients were diagnosed with advanced or late-stage disease, which has poorer outcomes and reduced survival; patients diagnosed with late-stage disease (III/IV) with a 2.0% five-year ASNS rate compared to patients diagnosed with early-stage disease (I/II) who had a five-year ASNS rate of 32.5% (NICR, 2023).

Risk Factors

Non-modifiable risk factors

Non-modifiable risk factors of pancreatic cancer include **increasing age**. In NI, the majority of patients (82.2% of patients diagnosed in 2016-2020) were aged over 55 years (NICR, 2023). **Males** are at a slightly higher risk of pancreatic cancer than females; in NI the age-standardised incidence rates between 2016 and 2020 were 20.1 cases per 100,000 for males and 13.9 cases per 100,000 for females, although this was not statistically significant (NICR, 2023).

People with early-onset **chronic pancreatitis** are at a greater risk of developing pancreatic cancer (Raimondi et al, 2010). In a large international study, **family history of pancreatic cancer** in a parent, sibling or child was associated with a significant 76% increased risk for developing pancreatic cancer (Jacobs et al, 2010).

Modifiable risk factors

The World Cancer Research Fund report on Diet, Nutrition, Physical Activity and pancreatic cancer judged that there was convincing evidence of an increased risk of pancreatic cancer in relation to excess **body fatness**, and probable evidence that **adult attained height** was associated with pancreatic cancer risk (the latter reflecting modifiable factors influencing growth in childhood) (WCRF/AICR, 2018). There is limited suggestive evidence that consumption of red and processed meat, heavy consumption of alcoholic drinks, and higher consumption of foods and beverages

containing fructose or foods containing saturated fatty acids are associated with pancreatic cancer risk (WCRF/AICR, 2018).

A large meta-analysis of 78 studies has confirmed that **tobacco smoking** is strongly associated with pancreatic cancer risk. Current smokers were found to have an 80% increased risk of pancreatic cancer, while former smokers had a 20% increased risk of pancreatic cancer, compared with non-smokers. However, the benefits of smoking cessation were shown to increase over time and analysis demonstrated that after 20 years of non-smoking, a previous smoker was at the same risk of pancreatic cancer as a non-smoker (Lugo et al, 2018).

Diabetes mellitus is a well-established risk factor for pancreatic cancer (Ben et al, 2011), and increasing attention is now being given to **new-onset diabetes** as an early manifestation of pancreatic cancer, which may lead to opportunities for earlier detection and screening for pancreatic cancer in this patient group (Henrikson et al, 2019).

Pancreatic cancer treatment

There are different types of pancreatic cancer treatment, and several types of surgery can be used to remove the tumour. The **Whipple procedure** is required for tumours in the head of the pancreas and involves the resection of the head of the pancreas, gallbladder, and the distal part of the stomach, small intestine and bile duct are also removed, but the pancreas can still produce digestive enzymes and insulin. A **total pancreatectomy** is another surgical option; this surgery removes the pancreas, part of the stomach and small intestine, the bile duct, gallbladder, spleen and nearby lymph nodes. A total pancreatectomy is less commonly performed but is necessary to treat patients with multi-site tumours or in patients with background pancreatic disease like main duct IPMN of the pancreas. A **distal pancreatectomy and splenectomy** is performed for tumours in the body and tail of the pancreas. When a tumour cannot be removed there are palliative surgeries that can be carried out to help improve quality of life. A **biliary bypass** can be performed if the tumour is blocking the bile duct and bile is building up in the gallbladder. An **endoscopic stent** could be used to drain the bile if the tumour is blocking the bile duct. A **gastric bypass** may be performed if the tumour is blocking the flow of food from the stomach. Systemic anticancer therapy and radiotherapy can also be used in the treatment of pancreatic cancer in the neo-adjuvant, adjuvant, or palliative setting. (NICE guideline NG85, 2018).

Pancreatic cancer can cause pancreatic exocrine insufficiency, which means that the pancreas has a deficiency of the pancreatic enzymes, lipase, elastase, amylase, trypsin and chymotrypsin, causing maldigestion and malabsorption and ultimately weight loss. (Brennan & Saif, 2019). UK guidelines therefore recommend that pancreatic enzyme replacement therapy (PERT) is used for all patients with pancreatic cancer to combat this by increasing the quality of life and maintaining the weight of the pancreatic cancer patients (NICE guideline NG85, 2018).

Aim and Methods

Audit Aim

This audit will:

1. Provide a **NI-wide dataset** on pancreatic cancer patients to **allow comparison with other national audits** of patient care and management.
2. Provide data to enable monitoring of **how cancer services compare** with the UK **NICE guidelines** (NICE guideline NG85, 2018) for diagnosis, multidisciplinary team management and management.
3. Assess how pancreatic cancer services have **changed from previous population-based audits** in NI (2001 and 2007) and to identify further areas for improvement.
4. Evaluate if any **potential inequalities** exist in treatments received by patients according to patient characteristics such as age, gender, socio-economic status and hospital trust of residence.
5. Assess the **impact of the COVID-19 pandemic** on services, clinical presentation and patient outcomes.

Methods

- Data items for collection were identified using the data dictionaries of the 2007 NICR Pancreatic Cancer Audit and NHS Scotland's HPB Quality Performance Indicators (QPIs) to allow comparability and were supplemented with a literature search of current professional guidelines. A custom database was developed by NICR IT staff to record the audit data items.
- Pancreatic cancer cases (ICD 0-3 code C25) with an incident date of diagnosis between 01/01/2019 and 31/12/2020 (two-year period) were extracted from NICR cancer registration systems.
- Datasets from the Regional Information System for Oncology and Haematology (RISOH), Patient Administrative system (PAS) and Radiotherapy datasets from both Northern Ireland Cancer Centres were linked to cancer registry data.
- A team of three NICR Cancer Intelligence Officers (CIOs) supplemented this dataset following review of the following electronic care systems:
    - The Multidisciplinary Team Meeting administration system – Cancer Patient Pathway System (CaPPS);
    - Labcentre: a regional database of all pathology reports in Northern Ireland.
    - RISOH-Regional Information System for Oncology and Haematology.
    - Northern Ireland Picture Archive and Communications System (NIPACS) and Belfast Trust Imaging systems. These systems store radiology scans and associated data.

Once the dataset was confirmed by the CIO team, Specialty Registrars in Surgery, Miss Dorothy Johnston and Miss Jessica Lockhart working with HPB Consultant Surgeon Mr Stephen McCain in the Belfast HSC Trust to then quality assure treatment data to include admission and discharge details, surgery type and surgical complications. Oncology data were also quality assured along with supportive care and follow up data. Miss Johnston also collected data where available on supportive care services. The data were then anonymised for analysis which took place in the secure environment of the NICR.

HSC Trust was determined by the patient's allocated primary Trust on CaPPS and where this was not available was determined by postcode of patient residence. This methodology ensured that patients who had treatments across multiple Trusts were not counted more than once and that the number of cases associated with Trusts was representative of the cohort of patients they have managed on their care pathway. Pancreatic cancer surgery is a centralised service within BHSCT.

Inclusion criteria for patients in the audit:

- All patients with a confirmed new incident primary cancer of the Pancreas (ICD-0-3: C25) diagnosed in 2019 and 2020 irrespective of cancer history of any site and histology.

Exclusion criteria:

- Patients with cancer of unknown primary origin.
- Patients with metastasis in the pancreas originating from another primary site.
- Patients with carcinoma-in-situ, non-invasive tumours, or dysplasia.
- Patients with a basis for diagnosis of death certificate only due to low volume of information.

Study Participants

There were 540 patients included in the audit, of which 257 were diagnosed in 2019 and 283 in 2020. Thirteen cases were excluded, with the two main reasons being insufficient diagnostic information due to Death certificate only (DCO) registration (5 patients, 38.5%), or that on CIO review the patient was allocated an "uncertain if a primary or secondary lesion" code (5 patients, 38.5%). There were more males than females diagnosed with pancreatic cancer with 283 males (52.3%) and 257 (47.6%) females (Table 1).

Table 1: Study Participants in the Pancreatic Cancer Audit 2019-2020, NI

	2019 n (%)	2020 n (%)	Total n (%)
Total Number of Patients	264 (47.7%)	289 (52.3%)	553 (100%)
Total Number of Exclusions	7 (2.7%)	6 (2.1%)	13 (2.4%)
Total Number in Audit Population	257 (47.6%)	283 (52.4%)	540 (100%)
Total Audit Population – Female:Male	126 (49.0%): 131 (51%)	131 (46.3%): 152 (53.7%)	257 (47.6%): 283 (52.4%)
Age at Diagnosis, years – median (range) Female Male All Persons	 73 (20-96) 71 (28-93) 72 (20-96)	 77 (46-94) 72 (38-96) 74 (38-96)	 74 (20-96) 72 (28-96) 73 (20-96)

Table 2: Mean age of pancreatic cancer diagnosis by sex for patients diagnosed 2019-2020, NI

	2019 n=257	2020 n=283	Total n=540
Female	72 years	75 years	74 years
Male	70 years	71 years	70 years

Mean age at diagnosis was significantly higher in females (74 years) than males (70 years) across both audit years (p=0.002). However, in comparing mean age by sex and year of diagnosis, the older age of females at diagnosis was only statistically significant in 2020 (p=0.005) and not 2019 (p=0.09).

Table 3: Frequency of pancreatic cancer patients by sex and audit year, NI

	2001 n=152 (%)	2007 n=172 (%)	2019 n=257 (%)	2020 n=283 (%)
Female	70 (46.1%)	77 (44.5%)	126 (49.0%)	131 (46.3%)
Male	82 (53.9%)	96 (55.5%)	131 (51.0%)	152 (53.7%)

Figure 4: Numbers of pancreatic cancer patients by sex and audit year, NI

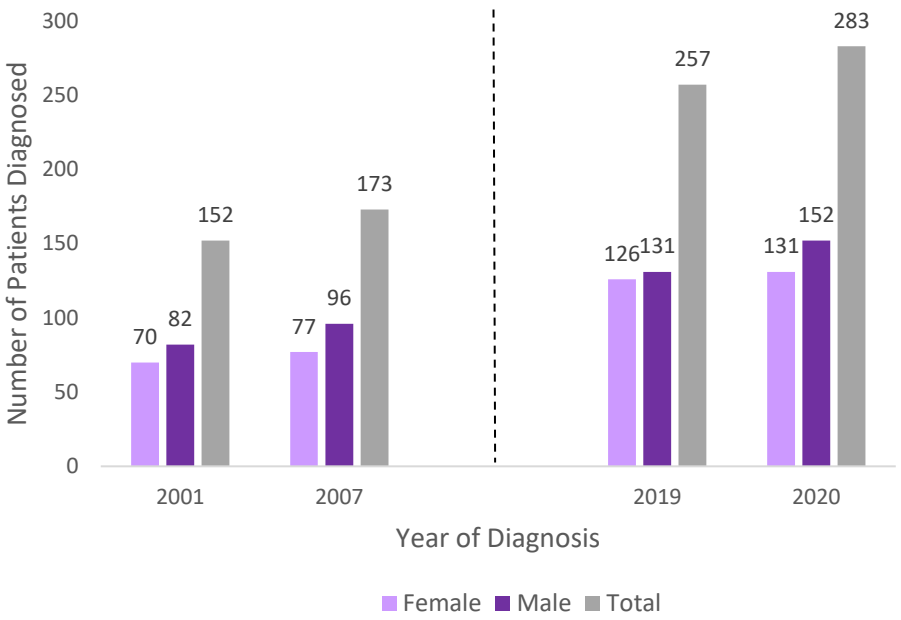


Table 3 and Figure 4 show the numbers of patients with a confirmed pancreatic cancer increased substantially between 2001 and 2020 with 152 patients diagnosed in 2001 compared with 283 in 2020. This represents an 86% rise in the number of patients being seen by pancreatic cancer services since the first NI audit of pancreatic cancer patients in 2001.

Table 4: Age and sex distribution of pancreatic cancer patients diagnosed 2019-2020, NI

Age group at diagnosis, years	Female n=257 (%)	Male n=283 (%)*	Total n=540 (%)
<50	9 (3.5%)	16 (5.7%)	25 (4.6%)
50-59	19 (7.4%)	30 (10.6%)	49 (9.1%)
60-69	57 (22.2%)	71 (25.1%)	128 (23.7%)
70-79	86 (33.5%)	94 (33.2%)	180 (33.3%)
80-89	70 (27.2%)	63 (22.3%)	133 (24.6%)
90+	16 (6.2%)	9 (3.2%)	25 (4.6%)

**Rounding error where percentages do not add up to 100%*

Figure 5: Age and sex distribution of pancreatic cancer patients diagnosed 2019-2020, NI

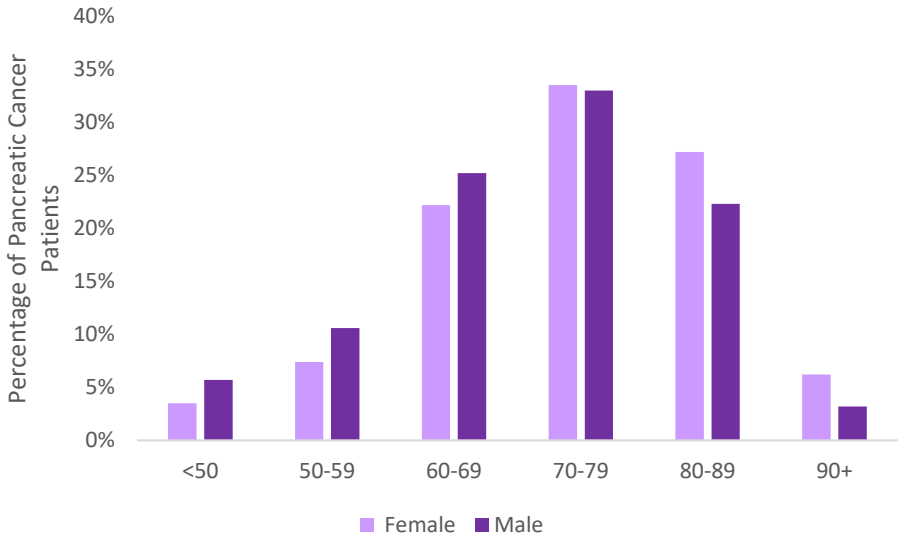


Table 4 and Figure 5 show that the majority of pancreatic cancer patients are 70 years of age or older when diagnosed (62.5%). Proportionally, there were more males in those less than 70 years and more females in those aged over 70 years.

Table 5: Distribution by socio-economic deprivation quintile of pancreatic cancer patients diagnosed 2019-2020, NI

Deprivation Quintile	No. Cases	Average no. Cases per Year	Crude incidence rate per 100,000 person years	European age-standardised incidence rate per 100,000 person years (95% confidence intervals)	Standardised Incidence ratio compared to NI (95% confidence intervals)	Statistical significance
Quintile 1 (Most deprived)	120	60	16.92	22.42 (18.4-26.5)	137.87 (114.3-164.9)	**Higher than NI Average**
Quintile 2	107	54	13.85	16.15 (13.1-19.2)	99.38 (81.4-120.1)	
Quintile 3	125	63	15.68	17.74 (14.6-20.9)	110.06 (91.6-131.1)	
Quintile 4	82	41	10.39	11.48 (9.0-14.0)	71.66 (57.0-88.9)	**Lower than NI Average**
Quintile 5 (Least Deprived)	106	53	14.55	14.49 (11.7-17.3)	90.30 (73.9-109.3)	
Total	540	270	14.22	16.10 (14.7-17.5)	100.00	

- The annual number of cases during 2019-2020 varied in each deprivation quintile due to variations in population size and age.
- After accounting for these factors, incidence rates in the most economically deprived areas were 38% higher than the NI average. This was consistent in both males and females (data not shown).

Table 6: Pancreatic cancer by histological subtype for patients diagnosed 2019-2020, NI

	2019 n=257 (%)	2020 n=283 (%)	Total n=540 (%)
Adenocarcinoma & Carcinoma NOS*	237 (92.2%)	269 (95.1%)	506 (93.7%)
Malignant Pancreatic Neuroendocrine tumour	20 (7.8%)	14 (4.9%)	34 (6.3%)

**NOS: Not otherwise specified*

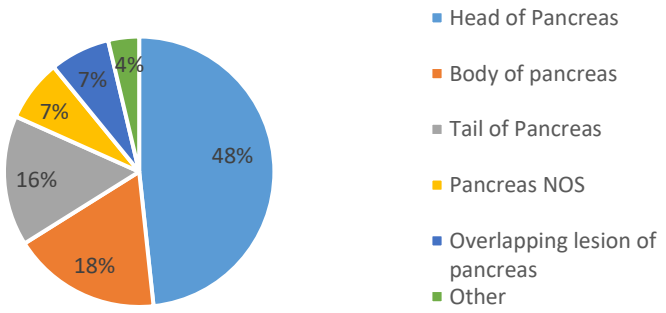
Table 6 shows there were 506 (93.7%) patients who were diagnosed with adenocarcinoma or a tumour which was NOS. Patients with a carcinoma NOS tumour are likely patients who did not have their cells examined by a pathologist. For the purposes of this audit carcinoma NOS and adenocarcinoma patient data were combined. There were 34 (6.3%) patients with a malignant pancreatic neuroendocrine tumour (pNET). In this audit adenocarcinoma & carcinoma NOS and pNET patients are separated for analysis where appropriate, as treatments and outcomes are very different between these groups.

Table 7: Anatomical tumour location on pancreas for patients diagnosed 2019-2020, NI

Location of Lesion	2019 n=257 (%)**	2020 n=283 (%)	Total n=540 (%)
Head of Pancreas	116 (45.1%)	145 (51.2%)	261 (48.3%)
Body of Pancreas	40 (15.6%)	56 (19.8%)	96 (17.8%)
Tail of Pancreas	45 (17.5%)	39 (13.8%)	84 (15.6%)
Other	10 (3.9%)	10 (3.5%)	20 (3.7%)
Overlapping Lesion of Pancreas	14 (5.5%)	25 (8.8%)	39 (7.2%)
Pancreas NOS*	32 (12.5%)	8 (2.8%)	40 (7.4%)

NOS: Not otherwise specified. Rounding error where percentages do not add up to 100%*

Figure 6: Anatomical tumour location on pancreas for patients diagnosed 2019-2020, NI



The most common anatomical location of malignant pancreatic tumours was the head of pancreas, with almost half (48.3%; n=261) of patients diagnosed with a tumour at this site (Table 7, Figure 6). Table 8 shows the distribution of patients based on Trust of treatment and Table 9 shows data by both Trust of residence and Trust of treatment. Trust of residence is determined by a patient's postcode and Health and Social Care (HSC) geographical boundaries. HSC Trust of treatment is determined by their assigned Trust according to the CaPPS. CaPPS is the multi-disciplinary team's administrative tool used to track cancer patient pathways and is used by the DoH NI to measure cancer waiting times which have associated targets for referral to treatment times. In this audit it is assumed that 'HSC Trust of Treatment' recorded on CaPPS is the Trust that assumed responsibility for a patient's care/patient pathway. NICR assessment found 25 pancreatic cancer patients did not have a CaPPS record.

Table 8: Distribution of pancreatic cancer patients diagnosed 2019-2020 by Primary Trust of Treatment, NI

Health and Social Care Trust of Treatment	Total Number of Patients n=540 (%)*
Belfast Trust	303 (56.1%)
Northern Trust	19 (3.5%)
South-Eastern Trust	62 (11.5%)
Southern Trust	80 (14.8%)
Western Trust	51 (9.4%)
Not on CaPPS	25 (4.6%)

**Rounding error where percentages do not add up to 100%.*

Table 9: Distribution of pancreatic cancer diagnosed 2019-2020 by Primary Trust of Treatment assigned by CaPPS and by Trust of residence determined by postcode of residence, NI

		HSC Trust according to CaPPS					
		Belfast	Northern	South Eastern	Southern	Western	**Total**
Trust of Residence	Belfast	81 (86.2%)	1	12	0	0	94
	Northern	118	17 (12.5%)	0	1	0	136
	South Eastern	48	0	49 (50.5%)	0	0	97
	Southern	33	0	1	78 (69.6%)	0	112
	Western	23	1	0	1	51 (67.1%)	76
	Total	303	19	62	80	51	515*

**Note that 25 patients did not have a CaPPS record*

- The blue cells in Table 9 show the proportion (%) of patients who are managed by an MDT within their area of residence.
- The majority of diagnostic and treatment pathways are managed by teams based in the patient's Trust of residence, except in Northern Trust where only 12.5% were managed within their Trust of residence. (Note that surgery is centralised to Belfast HSC Trust, as are some oncology services).
- During 2019-2020, the Belfast HSC Trust assumed treatment responsibility for the greatest number of pancreatic cancer patient's treatment pathways (n=303), followed by Southern Trust (n=80),South Eastern Trust (n= 62), Western Trust (n=51) and Northern Trust (n=19).

*Table 10. Pancreatic cancer cases diagnosed 2019-2020 by Trust of Treatment (CaPPS-assigned) and Trust of residence (determined by post code) for patients managed with **palliative intent***

		HSC Trust according to CaPPS					
		Belfast	Northern	South Eastern	Southern	Western	**Total**
Trust of Residence	Belfast	63 (82.9%)	1	12	0	0	76
	Northern	94	17 (15.2%)	0	1	0	112
	South Eastern	37	0	44 (54.3%)	0	0	81
	Southern	19	0	1	64 (76.2%)	0	84
	Western	14	1	0	1	42 (72.4%)	58
	Total	227 (55.2%)	19 (4.6%)	57 (13.9%)	66 (16.1%)	42 (10.2%)	411 (100%)

- Of the 411 patients who were managed with palliative intent, the Belfast HSC Trust team managed the majority (55.2%).
- In 4 of the 5 Trusts, over half of palliative patients had their care managed by local teams.
- However, in the Northern HSC Trust 83.9% of their palliative patients were managed by Belfast HSC Trust. (Note that 100% of patients residing in Northern HSC Trust and Belfast HSC Trust had their care managed by the Belfast HSC Trust if the treatment intent was curative).

Alcohol, Smoking and Family History

Table 11: Alcohol Consumption History by audit year of pancreatic cancer diagnosis, NI

	2001 n=152 (%)	2007 n=173 (%)	2019 n=257 (%)*	2020 n=283 (%)
Not Known	35 (23%)	24 (14%)	56 (21.8%)	50 (17.7%)
Current/Previous Drinker	71 (47%)	91 (52%)	116 (45.1%)	149 (52.6%)
Never Drinker	46 (30%)	58 (34%)	85 (33.1%)	84 (29.7%)

**Rounding error where percentages do not add up to 100%*

- Approximately half of pancreatic cancer patients have a history of current or previous alcohol consumption.
- Approximately 1 in 5 patients in the 2019-2020 audit did not have any information recorded regarding alcohol consumption in their clinical notes, thus the proportion of patients in the "Current/Previous Drinker" category is difficult to ascertain.

Table 12: Tobacco Smoking History by audit year of pancreatic cancer diagnosis, NI

	2001 n=152 (%)*	2007 n=173 (%)	2019 n=257 (%)*	2020 n=283 (%)*
Not Known	16 (11%)	8 (5%)	28 (10.9%)	17 (6.0%)
Current/Previous Smoker	83 (55%)	110 (63%)	116 (45.1%)	147 (51.9%)
Never Smoker	53 (35%)	55 (32%)	113 (44.0%)	119 (42.0%)

**Rounding error where percentages do not add up to 100%*

- Approximately half of pancreatic cancer patients had a clinical record of current or previous history of smoking.
- The proportion of current and previous smokers has reduced compared to 2007, while the proportion of never smokers has increased.

Table 13: Family History of cancer in pancreatic cancer patients diagnosed 2019-2020, NI

Family History of Pancreatic Cancer	2019 n=257 (%)	2020 n=283 (%)	Total n=540 (%)
Yes**	12 (4.7%)*	15 (5.3%)	27 (5.0%)
No	95 (37.0%)	91 (32.2%)	186 (34.4%)
Not Recorded	150 (58.4%)	177 (62.5%)	327 (60.6%)
Family History of Other Cancer			
Yes – 1st degree relative	59 (23.0%)*	54 (19.1%)*	113 (20.9%)
Yes – 2nd degree relative	11 (4.3%)	10 (3.5%)	21 (3.9%)
No	39 (15.2%)	40 (14.1%)	79 (14.6%)
Not Recorded	148 (57.6%)	179 (63.3%)	327 (60.6%)

**Rounding error where percentages do not add up to 100%*
***Includes both first degree relatives and second-degree relatives*

- The majority of patients (60.6%) had no record in their notes regarding family history of pancreatic cancer or a history of another cancer type.
- Only 5% of patients had a recorded family history of pancreatic cancer.
- Approximately 1 in 4 patients with pancreatic cancer had a recorded family history of a cancer other than pancreatic cancer.

Co-Morbidity

*Table 14: Co-morbidities at presentation by audit year of pancreatic cancer diagnosis, NI**

Co-Morbidities	2001 n=152 (%)	2007 n=173 (%)	2019 n=257 (%)	2020 n=283 (%)
Hypertension	50 (33%)	85 (49%)	122 (47.5%)	136 (48.1%)
Diabetes	29 (19%)	47 (27%)	74 (28.8%)	77 (27.2%)
Arthritis	32 (21%)	43 (25%)	26 (10.1%)	23 (8.1%)
Gallstones	37 (24%)	30 (17%)	33 (12.8%)	34 (12.0%)
Cerebrovascular Disease	15 (10%)	21 (12%)	9 (3.5%)	9 (3.2%)
COPD*	24 (16%)	15 (9%)	13 (5.1%)	23 (8.1%)
Chronic Pancreatitis	8 (5%)	14 (8%)	7 (2.7%)	7 (2.5%)
Dementia	-	12 (7%)	7 (2.7%)	8 (2.8%)
Other Malignancy	20 (13%)	31 (18%)	58 (22.6%)	60 (21.2%)
Asthma	-	-	17 (6.6%)	11 (3.9%)
Cardiovascular disease	-	-	184 (71.6%)	189 (66.8%)
Epilepsy	-	-	41 (16.0%)	35 (12.4%)
On Medication for/ Diagnosed with Mental Health Condition	-	-	106 (41.3%)	96 (33.9%)
Other Co-Morbidity	-	-	152 (59.1%)	147 (51.9%)

**Note some patients may have more than one co-morbidity*

- It should be noted that the methodology for collecting co-morbidity data changed relative to 2001 and 2007 when data was collected by manual note review.
- Over two thirds of patients had a cardiovascular related co-morbidity. Hypertension amongst patients diagnosed with pancreatic cancer has remained consistently high from 2007 (49%) through to 2020 (48.1%).
- Diabetes mellitus was diagnosed in 28.8% of pancreatic cancer patients diagnosed in 2019 and 27.2% of patients diagnosed in 2020; this was similar to 2007 figures and higher than 2001 figures.
- In 2019-2020 over one third of patients were either diagnosed or on medication within the mental health category of anxiety, depression and psychosis.
- There were high proportions of patients who had a comorbidity other than those listed at time of pancreatic cancer diagnoses in 2019 (59.1%) and 2020 (51.9%), as shown in Table 14 and Figure 7.

Figure 7: Frequency of reported co-morbidities in pancreatic cancer patients diagnosed 2019-2020, NI

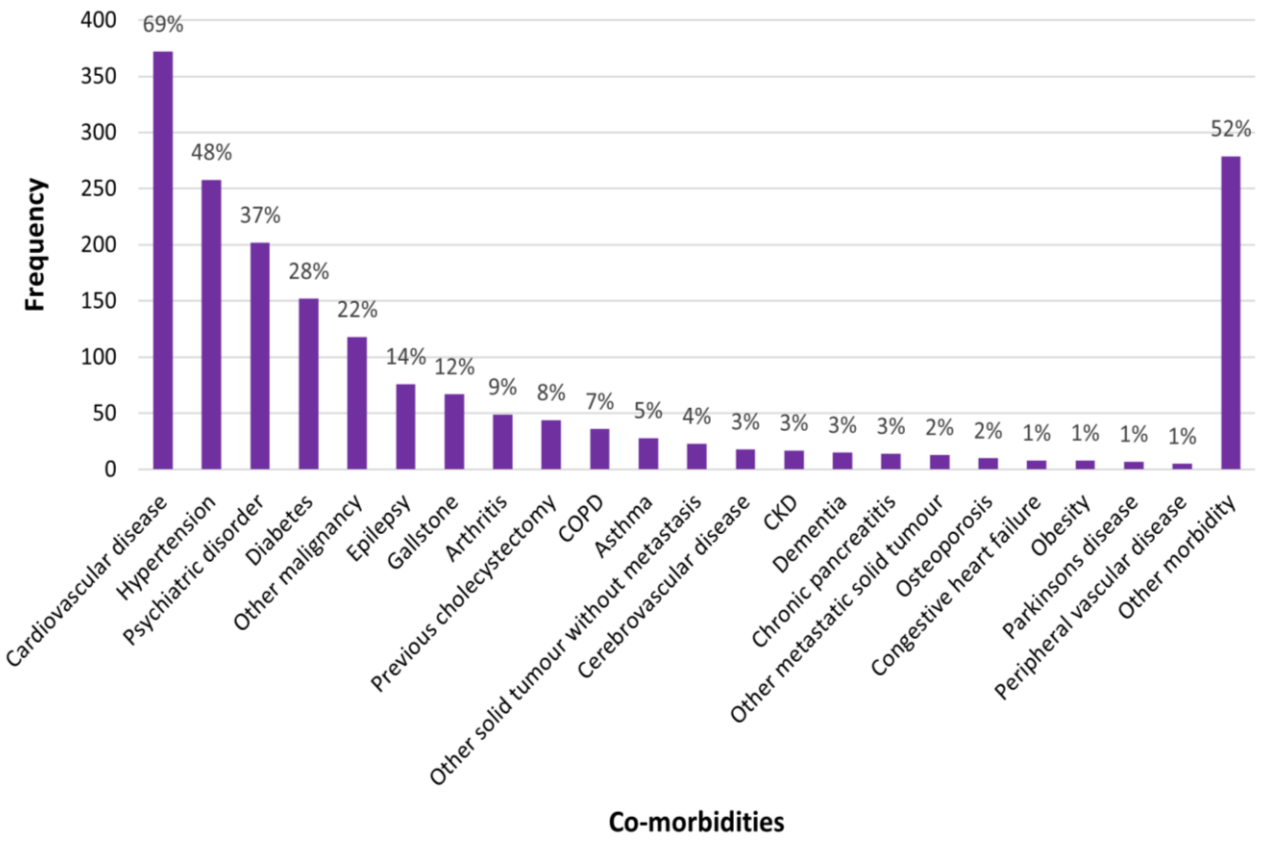


Table 15: Proportion of diabetic patients with insulin-controlled diabetes and age at diabetes diagnosis in pancreatic cancer patients by audit year, NI

	2001 n=29 (%)	2007 n=47 (%)	2019 n=74 (%)	2020 n=77 (%)
Insulin controlled diabetes	7 (24%)	20 (43%)	62 (84%)	64 (83%)
Age at diabetes diagnosis (years, median)	64	69	68	69

Table 16: Length of time from diabetes diagnosis to pancreatic cancer diagnosis by audit year, NI

	2001 n=29 (%)	2007 n=47 (%)	2019 N=74 (%)	2020 n=77 (%)
New Onset Diabetes, 0-12 months	12 (41%)	13 (28%)	10 (14%)	12 (16%)
12-24 months	3 (10%)	3 (6%)	7 (9%)	8 (11%)
More than 24 Months	14 (48%)	21 (45%)	44 (59%)	42 (55%)
2-5 years	-	-	14 (19%)	17 (22%)
5+ years	-	-	30 (41%)	25 (33%)
Duration not recorded	0 (0%)	10 (21%)	13 (18%)	14 (18%)

- In 2019-2020, of the average of 76 patients per year with pancreatic cancer who also had a recorded diagnosis of diabetes, over 4 in 5 of these patients had insulin-controlled diabetes (Table 15).
- Table 16 shows the duration between diabetes and pancreatic cancer diagnosis with the majority of patients (55%) having over 2 years between their diabetes and pancreatic cancer diagnosis.
- The proportion of patients diagnosed with new-onset diabetes (i.e. within a year prior to their pancreatic cancer) appears to have declined in recent years, however 14-16% of pancreatic cancer patients diagnosed in 2019-2020 were still recorded as having had a recent diabetes diagnosis.

Multi-morbidity and Medication at Presentation

Table 17: Prevalence of multi-morbidity in pancreatic cancer patients diagnosed 2019-2020, NI

	2019 n=257 (%)	2020 n=283 (%)*	Total n=540 (%)*
No Co-morbidities	15 (5.8%)	29 (10.3%)	44 (8.2%)
One Co-morbidity	27 (10.5%)	37 (13.1%)	64 (11.9%)
2-5 Co-morbidities	140 (54.5%)	137 (48.4%)	277 (51.3%)
5+ co-morbidities	75 (29.2%)	80 (28.3%)	155 (28.7%)

**Rounding error where percentages do not add up to 100%*

- Multi-morbidity is common among pancreatic cancer patients with 80% of patients having two or more comorbidities at diagnosis (Table 17).
- Multi-morbidity increases the complexity of pancreatic cancer care, especially with the potential for cancer treatments to exacerbate pre-existing co-morbidities.
- Table 18 shows the range of medications pancreatic cancer patients are taking for pre-existing conditions at cancer diagnosis.

Table 18: Medication history of pancreatic cancer patients diagnosed 2019-2020, NI

	2019 n=257 (%)	2020 n=283 (%)	Total n=540 (%)
Anticoagulants	49 (19%)	52 (18%)	101 (18.7%)
Aspirin	9 (4%)	6 (2%)	15 (2.8%)
Anti-Epilepsy Medication	41 (16%)	35 (12%)	76 (14.1%)
Anti-hypertensive	114 (44%)	119 (42%)	233 (43.2%)
Anti-secretory & mucosal proton pump inhibitor	174 (68%)	165 (58%)	339 (62.8%)
Cardio-vascular medication	184 (72%)	185 (65%)	369 (68.3%)
Respiratory medication	8 (3%)	13 (5%)	21 (3.9%)
Other medication	135 (53%)	117 (41%)	252 (46.7%)

- Overall, results shown in Table 17 and Table 18 highlight that care for pancreatic patients can be medically complex, and care for this patient group needs to be carefully considered on an individual and holistic basis.

Symptoms at Presentation

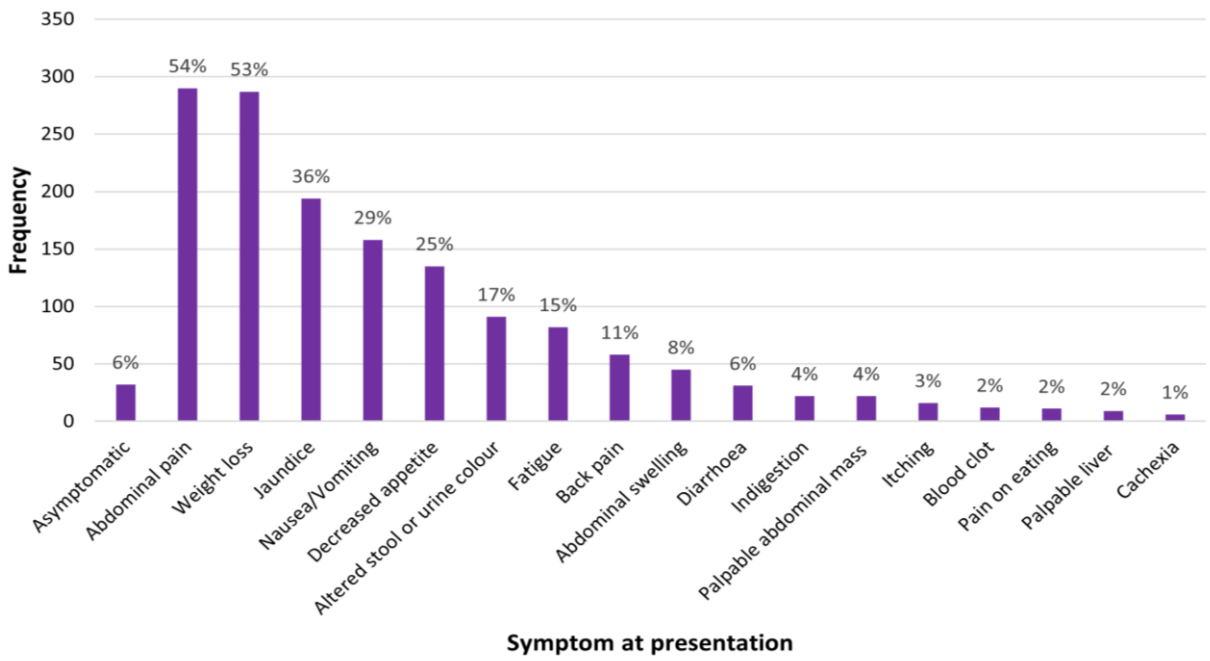
Table 19: Symptoms at presentation for pancreatic cancer patients by audit year, NI

Symptoms	2001 n=152 (%)	2007 n=173 (%)	2019 n=257 (%)	2020 n=283 (%)
Weight Loss	97 (64%)	120 (69%)	139 (54%)	148 (52%)
Loss of Appetite	99 (65%)	118 (68%)	69 (27%)	65 (23%)
Abdominal Pain	78 (51%)	109 (63%)	134 (52%)	156 (55%)
Jaundice	84 (55%)	90 (52%)	90 (35%)	104 (37%)
Nausea/Vomiting	78 (51%)	87 (50%)	69 (27%)	89 (31%)
Fatigue	44 (29%)	72 (42%)	42 (16%)	40 (14%)
Back Pain	36 (24%)	36 (21%)	23 (9%)	35 (12%)
Diarrhoea	23 (15%)	36 (21%)	17 (7%)	14 (5%)
Itching	33 (22%)	34 (20%)	7 (3%)	9 (3%)
Abdominal Swelling	-	32 (18%)	15 (6%)	30 (11%)
Palpable Abdominal Mass	25 (16%)	27 (16%)	8 (3%)	14 (5%)
Altered stool/urine colour	85 (56%)	93 (54%)	45 (18%)	46 (16%)
DVT/Blood clot	-	5 (3%)	7 (3%)	5 (2%)
Indigestion	-	-	7 (3%)	15 (5%)
Pain on Eating	-	-	6 (2%)	5 (2%)
Asymptomatic	-	-	23 (9%)	13 (5%)
Other symptom present	-	-	114 (44%)	122 (43%)

**Note some patients may have more than one symptom*

- Note the methodology for collecting co-morbidity data changed, as data in 2001 and 2007 were collected via manual note review, limiting comparability with 2019-2020 data collection.
- The most common symptoms that pancreatic cancer patients presented with in 2019-2020 were weight loss, abdominal pain, jaundice, loss of appetite or nausea/vomiting.
- Other symptoms reported in at least 1 in 10 pancreatic cancer patients diagnosed in 2019-2020 included fatigue, back pain, abdominal swelling and altered stool or urine colour.
- As shown in Figure 8, only 6% of pancreatic cancer patients diagnosed in 2019-2020 were considered to be asymptomatic.

Figure 8: Frequency of reported symptoms at presentation for pancreatic cancer patients diagnosed 2019-2020, NI



Stage at Diagnosis

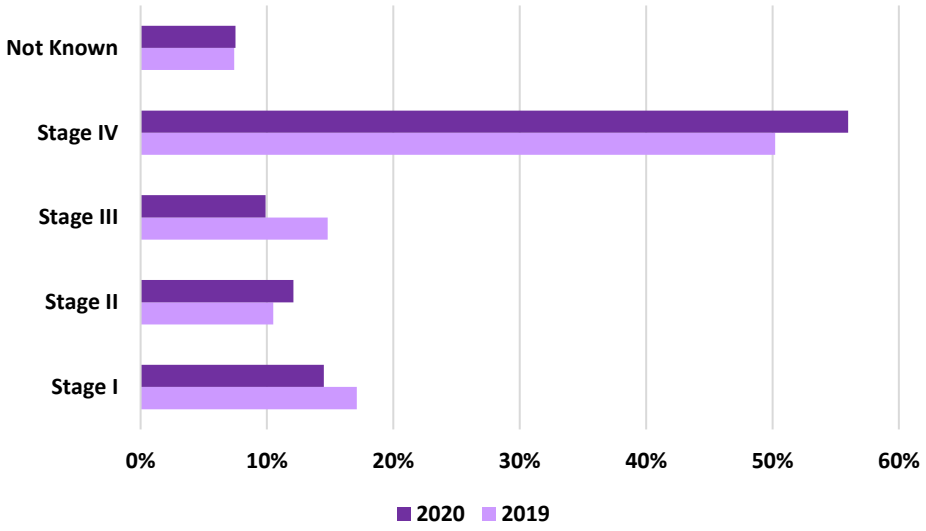
Table 20: Stage at diagnosis for pancreatic cancer patients diagnosed 2019-2020, NI

Stage	2019 n=257 (%)	2020 n=283 (%)*	Total n=540 (%)
Stage I	44 (17.1%)	42 (14.8%)	86 (15.9%)
Stage II	27 (10.5%)	34 (12.0%)	61 (11.3%)
Stage III	38 (14.8%)	28 (9.9%)	66 (12.2%)
Stage IV	129 (50.2%)	158 (55.8%)	287 (53.2%)
Not Known**	19 (7.4%)	21 (7.4%)	40 (7.4%)

**Rounding error where percentages do not add up to 100%*

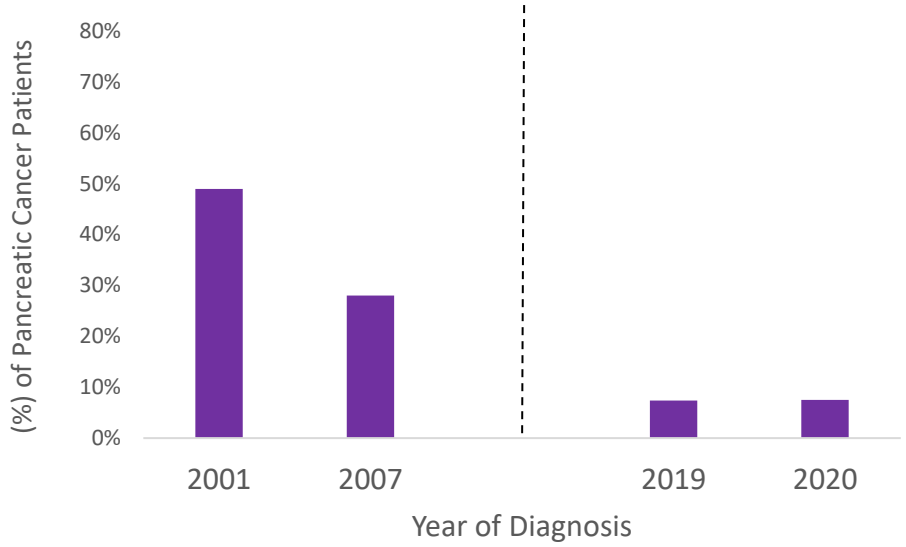
*** Stage Not Known due to incomplete staging investigations or level of disease progression unable to be clinically determine*

Figure 9: Stage at diagnosis for pancreatic cancer patients diagnosed 2019-2020, NI



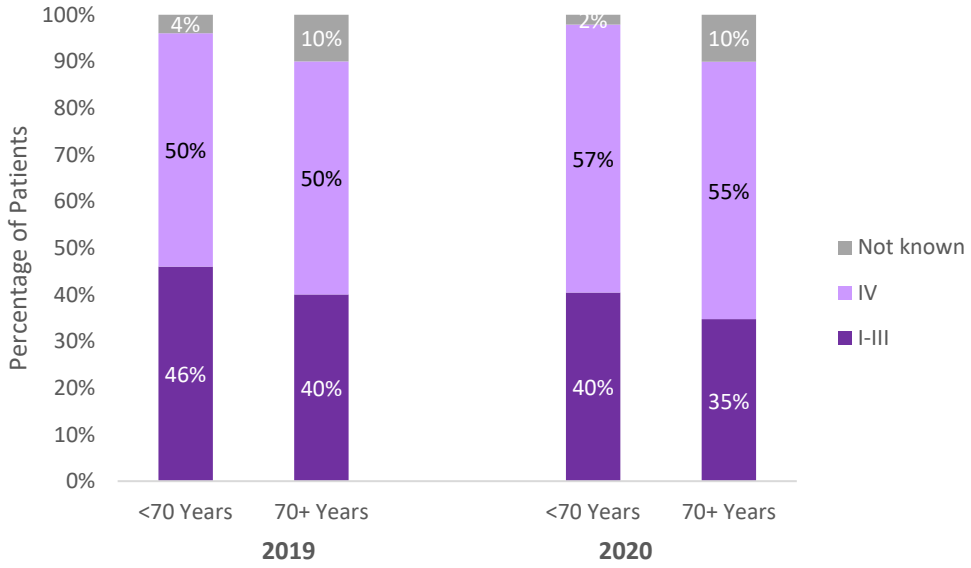
- The majority of patients diagnosed with pancreatic cancer in 2019-2020 were diagnosed at a late stage (IV) (53.2%), meaning that at diagnosis there was distant disease.
- In 2020 there was a 5.6% increase in the proportion of patients diagnosed with stage IV disease compared with 2019 with 55.8% of patients diagnosed stage IV in 2020 compared with 50.2% of patients in 2019.
- In 2020 there was a 4.9% reduction in stage III tumours diagnosed with 9.9% of patients having a stage III tumour compared with 14.8% in 2019.
- Difference in stage groups between 2019 and 2020 were not statistically significant (p=0.39).

Figure 10: The proportion of pancreatic cancer patients allocated a stage "Not Known" by audit year, NI.



- In 2001 49% of pancreatic cancer patients had an unknown stage of disease at diagnosis, which declined to 28% for patients diagnosed in 2007, and further declined to 7.4% for patients diagnosed in 2019-2020. This indicates major improvements in staging of pancreatic cancers over this timeframe.

Figure 11: Stage distribution by age group in pancreatic cancer patients diagnosed 2019-2020, NI



**Rounding error where percentages do not add up to 100%*

- Figure 11 shows that older pancreatic cancer patients (70 years or older) have a higher proportion with unknown stage compared with younger patients.
- A higher proportion of younger patients (aged 70 years or less) have stage I-III disease compared with patients diagnosed at 70 years or older, irrespective of year of diagnosis.
- Younger patients aged <70 years and older patients aged 70+ years both had a reduction in the proportion of allocated stage I-III in 2020 in comparison with 2019.
- While both patients aged under 70 and over 70yrs had increased proportions with stage IV disease in 2020 compared with 2019, patients under 70 had a greater increase (7%) compared with patients aged 70 and over (5%). However, this was not statistically significant (p=0.18).

Referral & MDT

Table 21: Source of Referral for pancreatic cancer patients diagnosed 2019-2020, NI

Source of referral	2019 n=*(%)	2020 n=270**(%)
Direct from GP	66 (26.9%)	101 (37.4%)
GP to A&E	<5	15 (5.6%)
Emergency Admission	106 (43.3%)	115 (42.6%)
Referral to outpatients via other outpatient clinic	31 (12.7%)	22 (8.2%)
Other	34 (13.9%)	17 (6.3%)
Not Known	6 (2.5%)	0 (0.0%)

**Total removed as small numbers can be inferred*
***Note 25 patients did not have a CaPPS record*

- Table 21 above shows the method of referral to pancreatic cancer services. The data for this table were collected via CaPPS by the CIO team.
- The main method of referral for pancreatic cancer patients diagnosed 2019-2020 was via emergency admission.
- In 2020 the numbers of patients presenting to Accident and Emergency units across NI via their GP increased from <5 patients in 2019 to 15 in 2020.
- Of the 51 patients diagnosed with pancreatic cancer in 2019-2020 with "other" as their recorded source of referral, 28% were admitted as an inpatient for another medical condition and 26% were an incidental finding of a pancreatic tumour.

Table 22: Frequency of patients with a hospital stay 30 days prior to their date of diagnosis for pancreatic cancer patients diagnosed 2019-2020, NI

Hospital Stay	2019 n=257 (%)	2020 n=283 (%)	Total n=540* (%)
No Hospital Stay	63 (24.5%)	58 (20.6%)	121 (22.4%)
Elective Admission	112 (43.6%)	105 (37.2%)	217 (40.2%)
Emergency Admission	82 (31.9%)	110 (39.0%)	192 (35.6%)
Not Known	0 (0%)	10 (3.2%)	10 (1.9%)

**Rounding error where percentages do not add up to 100%*

- Table 22 shows the number of patients who had an admission to hospital for any medical reason up to 30 days prior to their date of diagnosis. The data for this measure are sourced from NICR official statistics. It is worth noting that for some patients they will be diagnosed during an elective (planned) medical procedure to alleviate/investigate a symptom, for others it could be an incidental finding.
- Just over one third of pancreatic cancer patients had an emergency admission in the 30 days prior to their date of diagnosis.

- The proportion of patients who had an emergency admission increased in 2020 by 7.1%, when those who do not have a hospital stay record are excluded, this increase is not statistically significant (p=0.13).
- Table 23 shows that approximately two thirds pancreatic cancer patients who had an emergency admission were diagnosed with stage IV disease, whereas 50.5% of patients who had an elective admission were diagnosed at an earlier stage I-III.

Table 23: Frequency of patients with a hospital stay 30 days prior to their date of diagnosis by stage for pancreatic cancer patients diagnosed 2019-2020, NI

Hospital Stay	Stage I-III n=206 (%)	Stage IV n=287 (%)	Stage Not Known n=38 (%)
Emergency Admission n=192 (%)	50 (26.0%)	128 (66.7%)	14 (7.3%)
Elective Admission n=218 (%)	110 (50.5%)	98 (44.9%)	10 (4.6%)
No Hospital Stay n=121 (%)	46 (38.0%)	61 (50.4%)	14 (11.6%)

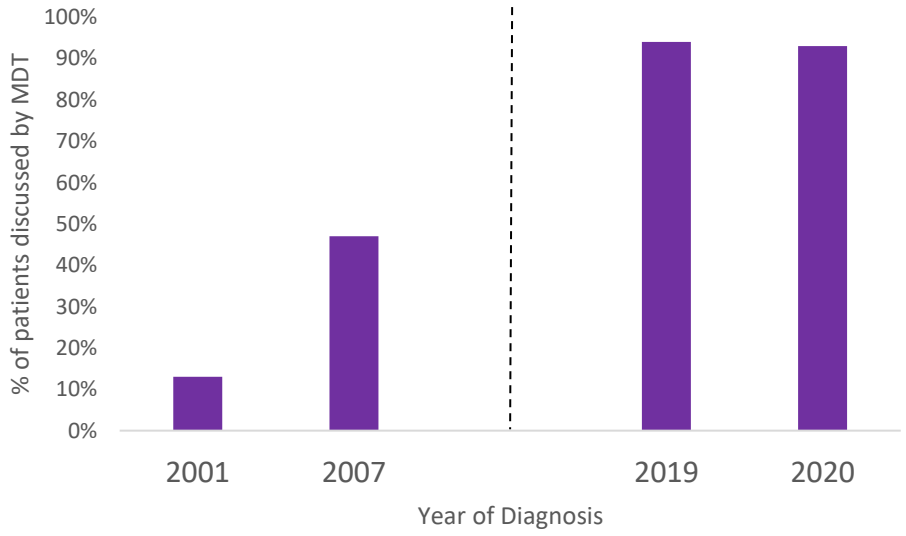
Multi-Disciplinary Team Meeting

Multi-disciplinary team (MDT) meetings involve a group of health professionals from a range of clinical specialities which give advice and make decisions on recommended treatments to ensure the best standard of care taking into account patient's individual care requirements.

Table 24: Frequency of pancreatic cancer patients discussed at MDT by audit year, NI

	2001 n=152 (%)	2007 n=173 (%)	2019 n=257 (%)	2020 n=283 (%)
Discussed	20 (13.2%)	82 (47%)	242 (94.2%)	262 (92.6%)
Not Discussed	132 (86.8%)	98 (57%)	15 (5.8%)	21 (7.4%)

Figure 12: Proportion of pancreatic cancer patients discussed at MDT by audit year, NI



- Since 2001 there has been a large increase in the proportion of patients discussed by an MDT with 13.2% of patients discussed in 2001 compared with 92.6% in 2020.
- The number of patients being discussed annually has increased from only 20 in 2001 to 262 in 2020.
- Of the 36 patients during 2019-2020 who did not have an MDT discussion, 25 (69.4%) did not have a CaPPS record.
- Of the 36 patients during 2019-2020 who did not have an MDT discussion, 20 (55.6%) died within 2 weeks after their date of diagnosis.
- Of all pancreatic patients diagnosed 2019-2020 who underwent treatments of surgery, chemotherapy or radiotherapy, 99% had their first MDT prior to first treatment. This shows good practice in ensuring a patient-centred approach to treatment options for all patients.

Staging Investigations

Table 25: Frequency of pancreatic cancer patients having staging investigations by audit year, NI

	2001 n=152 (%)	2007 n=173 (%)	2019 n=257 (%)	2020 n=283 (%)
CT-scan	123 (81%)	161 (93%)	254 (98.8%)	277 (97.8%)
PET-CT-scan	No data	8 (5%)	14 (5.5%)	22 (7.8%)
MRI Scan	No data	6 (3%)	44 (17.1%)	47 (16.6%)
MRCP Scan	4 (3%)	18 (10%)	68 (26.5%)	65 (23.0%)
Endoscopic Ultrasound (EUS)	No data	21 (12%)	78 (30.4%)	66 (23.3%)
Endoscopic Retrograde Cholangiopancreatography (ERCP)	110 (71%)	84 (49%)	95 (37.0%)	105 (37.1%)
Percutaneous transhepatic cholangiogram (PTC)	21 (14%)	17 (10%)	23 (8.9%)	26 (9.2%)

- The number of CT scans performed on pancreatic patients across NI increased from 123 in 2001 to 277 in 2020 representing a 124% increase over a 19-year period.
- The proportion of patients that have a CT scans performed has also increased in this period with 81% of patients scanned in 2001, compared to 98.3% in 2019-2020.
- Between 2007 and 2020 there was a modest increase in the proportion of pancreatic cancer patients having a PET-CT Scan.
- MRCP is a type of MRI which uses computer software to better assess pancreatic and bile duct blockages. It produces a similar image to ERCP but is less invasive. The use of MRCP increased between 2001 and 2019/2020.
- Endoscopic Ultrasound (EUS) is recommended for patients where further information is required to determine tumour and node staging. In 2019/20 there was an average of 72 EUS performed per year, an increase of 243% since 2007 (n=21). In 2020 there were 12 fewer EUS procedures carried out compared to 2019, but this was not statistically significant (p=0.07).
- ERCP can be used as a diagnostic tool by enabling tissue sampling and also for treatment to allow biliary drainage. More detail on ERCP as a therapeutic intervention is on p42. The number of patients receiving ERCP has remained consistent between 2001 and 2020, with an average of 100 procedures per year in 2019-2020. Proportionally, the number of ERCP procedures has decreased since 2001 by 34%, with this decrease in part due to the rise in MRCP use.
- In cases where ERCP is not able to achieve biliary drainage then Percutaneous Transhepatic Cholangiogram (PTC) is a valuable alternative. PTC is also useful in assessing the degree of tumour involvement. The numbers of patients receiving PTC has remained relatively consistent between 2001 and 2019/2020.

NICE Guidelines NG85 (2018) Specific advice on Pancreatic Cancer Staging Investigations

Staging CT Advice

NICE guidelines NG85 (2018) recommend that: "For patients with newly diagnosed pancreatic cancer who have not had a pancreatic protocol CT scan, offer a pancreatic protocol CT scan that includes the chest, abdomen and pelvis".

Table 26: Frequency of patients who received a pancreatic protocol CT of chest, abdomen and pelvis (CT CAP) as per NICE Guidelines NG85 for pancreatic cancer patients diagnosed 2019-2020, NI

	2019 n=257 (%)	2020 n=283 (%)	Total n=540 (%)
Patients that received CT of chest, abdomen and pelvis	199 (77.4%)	202 (71.4%)	401 (74.3%)

- The majority of patients (74.3%) received a pancreatic protocol CT CAP, which increased information available for full tumour staging.
- The proportion of patients who received CT CAP in 2019 (77.4%) was higher than in 2020 (71.3%), but this difference was not significant (p=0.11).
- Of patients who received a CT scan, 35 (13.8%) in 2019 and 51 (18.5%) in 2020 were without pelvic scanning.

PET-CT Scanning Advice

NICE guidelines NG85 (2018) recommend that fluorodeoxyglucose positron emission-CT-scanning (FDG-PET/CT) is offered to patients who have localised disease on CT scanning who will be having treatment (surgery, radiotherapy and systemic therapy).

Table 27: Frequency of patients with incident stage I-III pancreatic cancer treated with curative intent (surgery, radiotherapy or chemotherapy) who received FDG-PET/CT diagnosed 2019-2020, NI

	2019 n=* (%)	2020 n=36(%)	Total n=90 (%)
Patients that received FDG-PET/CT	<5	12 (33.3%)	15 (16.7%)

**Numbers obscured due to low numbers policy to prevent disclosure*

- The proportion of patients with localised disease who received either surgery, chemotherapy or radiotherapy with curative intent that had a staging FDG-PET/CT was low, with an average of 16.7% over 2019-2020.
- The proportion of patients receiving a FDG-PET/CT was significantly higher in 2020 (33.3%) compared to 2019 (5.6%) (p=0.001), with this increase likely due to PET-CT being first commissioned for pancreatic staging investigations in 2020.

Suspected Liver Metastasis Advice

Staging Investigations

NICE guidelines NG85 (2018) advise that "If more information is needed to decide the person's clinical management consider an MRI for suspected liver metastases or laparoscopy with laparoscopic ultrasound if resectional surgery is still a possibility".

Table 28: Frequency of patients with suspected liver metastases at diagnosis for pancreatic cancer patients diagnosed 2019-2020, NI

Liver metastases suspected?	2019 n=257 (%)	2020 n=283 (%)	Total n=540 (%)
Yes	53 (20.6%)	89 (31.5%)	142 (26.3%)
No	204 (79.4%)	194 (68.5%)	398 (73.7%)

- During initial work-up in 2019-2020 approximately a quarter of patients had a suspected liver metastasis at diagnosis.
- In 2020 there was an additional 36 patients with a suspected liver metastasis compared with 2019. This represents a statistically significant proportional increase of 11% (p=0.004).

Table 29: Frequency of pancreatic cancer patients with suspected liver metastases at MDT who had an MRI and survived more than 30 days after diagnosis date in 2019-2020, NI

	2019 n=34 (%)	2020 n=72 (%)	Total n=106 (%)
MRI	17 (50.0%)	23 (31.9%)	40 (37.7%)
No MRI	17 (50.0%)	49 (68.1%)	66 (62.3%)

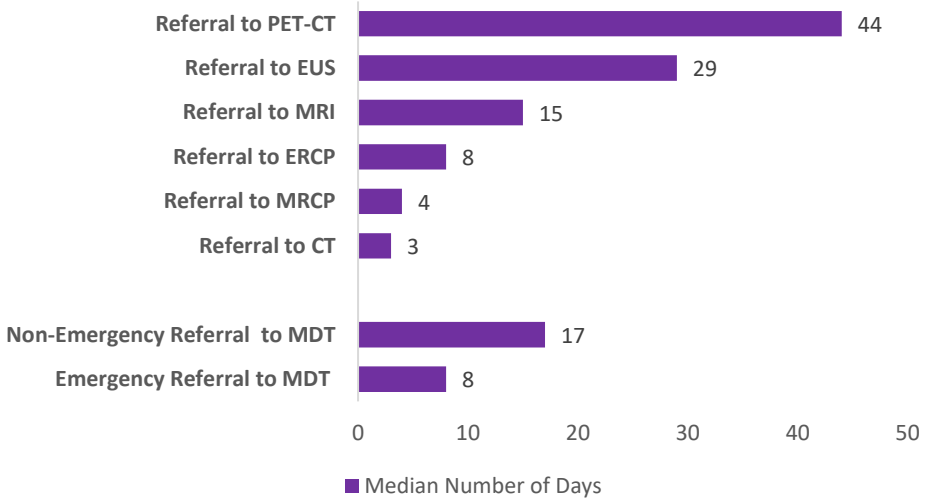
- In total there were 142 pancreatic cancer patients who has suspected liver metastasis during their investigative work-up in 2019-2020, of these 106 patients survived more than 30 days.
- There was a reduction in the proportion of patients with suspected liver metastasis who had an MRI scan in 2020 (31.9%) compared to 2019 (50.0%), but this difference was not statistically significant (p=0.07).
- Note that data on laparoscopy with ultrasound was unavailable for data collection.

*Table 30: Timelines to staging investigations for pancreatic cancer patients diagnosed 2019-2020, NI**

**Note a valid date of referral and investigation needed to be available for inclusion in this table*

Figure 13: Median timelines from referral to MDT and diagnostic procedures for pancreatic cancer patients diagnosed 2019-2020, NI

	2019	2020	2019-2020
Referral to MDT (median)	11 days	9 days	10 days
Referral to MDT (IQR p25-p75)	6-20 days	6-21 days	6-20 days
Referral to MDT (Emergency referral median)	8 days	7 days	8 days
Referral to MDT (Non-emergency referral median)	14 days	18 days	17 days
Referral to CT (median)	3 days	2 days	3 days
Referral to CT (IQR p25-p75)	0-11 days	0-10 days	0-10 days
Referral to MRCP (median)	5 days	4 days	4 days
Referral to MRCP (IQR p25-p75)	2-9 days	1-13 days	1-10 days
Referral to ERCP (median)	9 days	7 days	8 days
Referral to ERCP (IQR p25-p75)	4-22 days	4-17 days	4-17 days
Referral to MRI (median)	21 days	14 days	15 days
Referral to MRI (IQR p25-p75)	0-51 days	3-36 days	0-43 days
Referral to EUS (median)	29 days	31 days	29 days
Referral to EUS (IQR p25-p75)	8-41 days	21-54 days	21-45 days
Referral to PET-CT (median)	-	-	44 days
Referral to PET-CT (IQE p-25-p75)	-	-	30-63 days



- Table 30 and Figure 13 show the median time taken from referral to date of MDT staging investigations. Note that not all patients receive an investigation, and some patients may receive more than one investigation. This data excluded anyone who had an investigation completed prior to 30 days before date of referral. This is because investigation results (such as CT scan reports) are often used within the referral letter to inform the clinical staff at the MDT about the case. There will be times where it is clinically appropriate for patients not to undergo immediate investigation. Note that PET scan results are not split by year due to low numbers of patients having this procedure.
- Of patients referred for MDT, the MDT meeting took place a median of 10 days following referral. This varied by admission route with patients referred via emergency admission discussed within a median of 8 days, compared to 17 days for patients referred via non-emergency routes, with this difference being significant ($p<0.001$).
- Patients referred via non-emergency routes had longer wait times in 2020 compared to 2019 (median 3 days extra), although this difference was not significant ($p=0.42$).
- In 2020 there were improvements in times from referral to a variety of diagnostic investigations - CT scan, ERCP, MRCP and MRI. The largest improvement in wait time was for MRI with patients diagnosed in 2020 waiting on average one week less than patients diagnosed in 2019, although this difference was not significant ($p=0.68$).
- In 2020 wait time for EUS increased by a median of 2 days compared to 2019, although again this difference was not significant ($p=0.68$).
- Patients had their initial CT scan within a median of three days of being referred to MDT.
- For patients who required EUS as a part of their staging work-up, the waiting time from referral to EUS was approximately one month (29 days).
- Patients who required PET as a-part of their staging work-up wait, the median waiting time from referral was 44 days.

Time to Clinical Diagnosis

Table 31: Median time from referral to diagnosis by referral route for pancreatic cancer patients diagnosed 2019-2020, NI

	Referral time to diagnosis 2019		Referral time to diagnosis 2020	
	Median	IQR p25-75*	Median	IQR p25-75*
Red Flag Referral (n=132)	33 days	18 – 59 days	27 days	17 - 47 days
Emergency Admission (n=244)	9 days	1 – 21 days	7 days	0 - 19 days

**Interquartile range 25%-75%. Date of diagnosis is defined as the NICR Date of diagnosis. Patients without a valid date of referral were excluded (n=4)*

- Time to diagnosis is longer for patients diagnosed via red-flag referral compared to emergency admission by approximately 3 weeks (24 days in 2019, 20 days in 2020).
- In 2020, time to diagnosis for red flag referrals was a median 6 days shorter than in 2019, although this difference was not statistically significant (p=0.18).
- In 2020, time to diagnosis was a median 2 days shorter for patients referred via an emergency route, although this difference was not statistically significant (p=0.45).

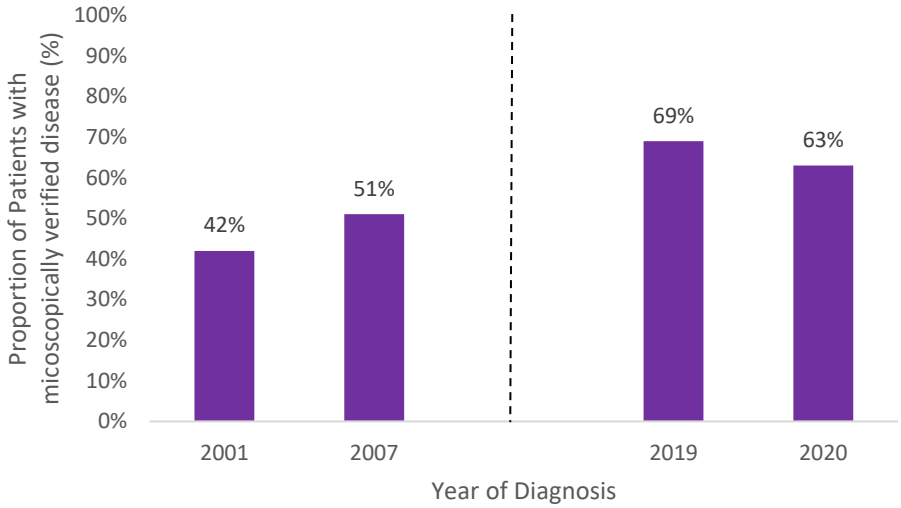
Tumour Characteristics

Microscopic verification of cancer, which involves the analysis of cancer cells in a pathology laboratory, is the key means to support accurate cancer staging and diagnosis.

Table 32: Frequency of microscopically verified pancreatic cancer patients by audit year, NI

	2001 n=152 (%)	2007 n=173 (%)	2019 n=257 (%)	2020 n=283 (%)
Microscopically verified	64 (42%)	88 (51%)	177 (68.9%)	179 (63.3%)

Figure 14: Proportion of patients with microscopically verified pancreatic cancer by audit year, NI



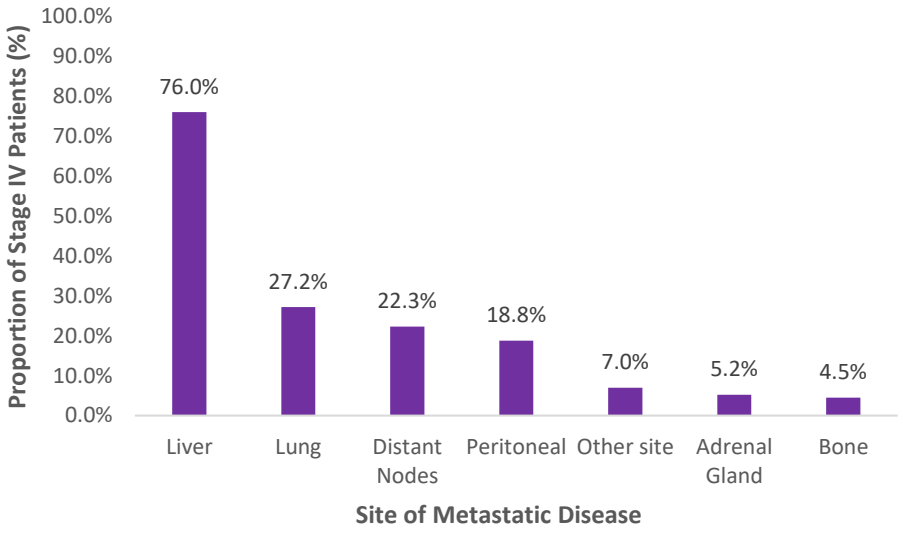
- The proportion of patients with microscopically verified diagnosis has increased over time since 2001.
- The proportion of patients with microscopically verified diagnosis was 68.9% in 2019 and 63.3% in 2020. Between 2001 and 2019 microscopically verified diagnosis rates rose from 42% to 69%. It is worth noting that for some patients with advanced disease or multi-morbidity microscopic verification may not be suitable or possible as the procedure to retrieve pancreatic cancer cells may be too invasive.
- The number of cases with microscopically verified diagnosis has increased by 114 between 2001 and 2020, which represents a rise of 178% cases being processed by NI pathologists in this timeframe.

*Table 33: Site of metastatic disease in stage IV pancreatic cancer patients by audit year, NI**

Site of Metastatic Disease	2001 n=59 (%)	2007 n=92 (%)	2019 n=129 (%)	2020 n=158 (%)
Liver	52(88%)	66 (72%)	97 (75.2%)	121 (76.6%)
Lung	4 (7%)	8 (9%)	30 (23.3%)	48 (30.4%)
Peritoneum	3 (5%)	22 (24%)	27 (20.9%)	27 (17.1%)
Bone	-	-	7 (5.4%)	6 (3.8%)
Distant Nodes	-	-	21 (16.3%)	43 (27.2%)
Adrenal Gland	-	-	6 (4.7%)	9 (5.7%)
Other	-	-	11 (8.9%)	8 (5.4%)

**Note some patients may have more than one location of metastatic disease*

*Figure 15: Site of metastatic disease in stage IV pancreatic cancer diagnosed 2019-2020, NI**



**Note some patients may have more than one site of metastatic disease*

- Table 33 and Figure 15 show the site of metastatic disease for pancreatic cancer patients. The liver remains the most common site of metastatic disease with 88% of patients having liver metastases in 2001, and 76% of patients in the current audit (2019-2020).

Treatment

Endoscopic/Radiologic Intervention

A biliary stent allows for bile to flow into the small intestine following a blockage. During 2019-2020, as shown in Table 34, 28.3% of pancreatic cancer patients required this procedure via ERCP with similar proportions for both years. Biliary stents can be used to relieve symptoms of blockage or prior to resectional surgery.

Table 34: Proportion of patients treated with a biliary stent fitted by an endoscopist for pancreatic cancer patients diagnosed 2019-2020, NI

ERCP Stent Placed	2019 n=257 (%)	2020 n=283 (%)	Total n=540 (%)
Yes	73 (28.4%)	80 (28.3%)	153 (28.3%)
No/Not Known	184 (71.6%)	203 (71.7%)	387 (71.7%)

Duodenal stents are mainly utilised to relieve symptoms in patients who are unable to have their tumour resected. In total, 2.6% of pancreatic patients diagnosed in 2019-2020 had duodenal stent insertion, as shown in Table 35.

Table 35: Proportion of patients treated with a duodenal stent fitted by an endoscopist for pancreatic cancer patients diagnosed 2019-2020, NI

Duodenal Stent Fitted	2019 n=257 (%)	2020 n=283 (%)	Total n=540 (%)
Yes	6 (2.3%)	8 (2.8%)	14 (2.6%)
No	240 (93.4%)	270 (95.4%)	510 (94.4%)
Not Known	11 (4.3%)	5 (1.8%)	16 (3.0%)

Treatment Plan

Table 36 shows 80.7% of pancreatic cancer patients representing approximately 4 out of 5 patients were treated with palliative intent. In 2020 the proportion of patients treated with palliative intent increased significantly by 11.5% (p=0.001) compared with patients diagnosed in 2019.
The majority of adenocarcinoma & carcinoma NOS patients are treated with palliative intent (83.2%). However, the majority of patients with a malignant neuroendocrine tumour are treated with curative intent (55.9%).

Table 36: Treatment Plan Intent histology type for patients diagnosed with pancreatic cancer 2019-2020, NI

Treatment intent	Adenocarcinoma & Carcinoma NOS			Malignant Neuroendocrine Tumours			Total		
	2019 n=237 (%)	**2020** n=269 (%)	**Total** n=506 (%)	**2019** n=20 (%)	**2020** n=14 (%)	**Total** n=34 (%)	**2019** n=257 (%)	**2020** n=283 (%)	**Total** n=540 (%)
Curative	51 (21.5%)	34 (12.6%)	85 (16.8%)	14 (70.0%)	5 (35.7%)	19 (55.9%)	65 (25.3%)	39 (13.8%)	104 (19.3%)
Palliative	186 (78.5%)	235 (87.4%)	421 (83.2%)	6 (30.0%)	9 (64.3%)	15 (44.1%)	192 (74.7%)	244 (86.2%)	436 (80.7%)

Palliative treatment in this audit is classified in two categories, non-curative anti-cancer and best supportive care. Please see definitions below and Table 37 for proportions.

Non-curative (anti-cancer) intent refers to treatment that is not curative but is designed to reduce disease load on the patient typically by aiming to reduce either the primary tumour or secondary tumours. This is mainly associated with patients treated with palliative oncology (chemotherapy or radiotherapy).

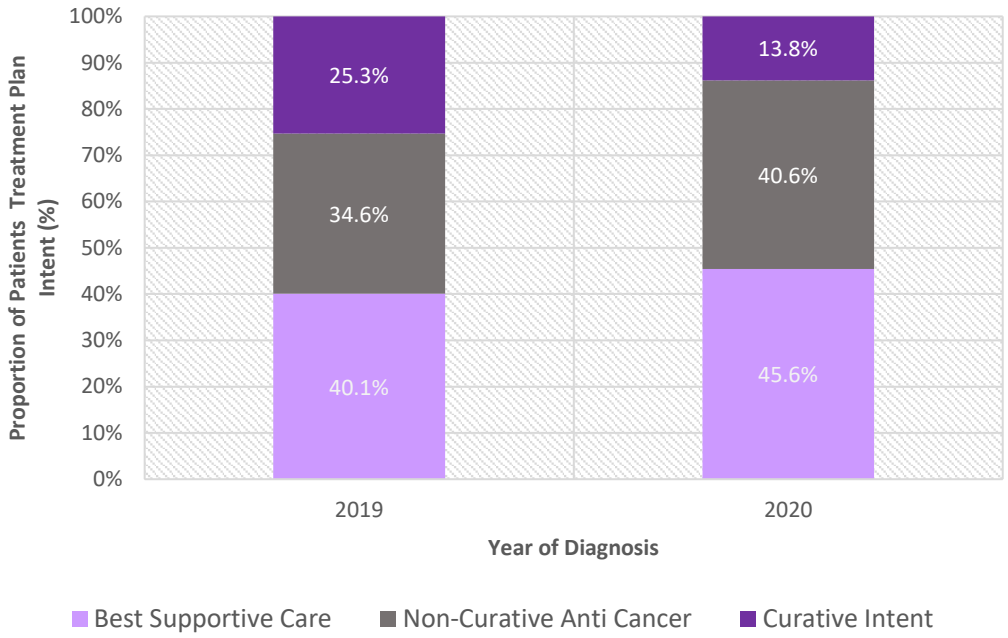
No Active Treatment (Best Supportive Care – BSC). Patients in this category do not have a plan for any tumour reductive treatments such as tumour-removing surgery, or oncology.

Table 37: Treatment Plan Intent for pancreatic cancer patients diagnosed 2019-2020, NI

Treatment Plan Intent	Treatment Plan Intent	2019 n=257 (%)	2020 n=283 (%)	Total n=540 (%)*
Curative	Curative Intent	65 (25.3%)	39 (13.8%)	104 (19.3%)
Palliative	Non-Curative (Anti-cancer)	89 (34.6%)	115 (40.6%)	204 (37.8%)
	No Active Treatment (Best Supportive Care)	103 (40.1%)	129 (45.6%)	232 (43.0%)

*Rounding error where percentages do not add up to 100%

Figure 16: Treatment plan intent for patients diagnosed with pancreatic cancer 2019-2020, NI



- The proportion of patients with a recommended treatment plan which is non-curative anticancer (palliative oncology) increased by 6.2% in 2020 compared with 2019. This is an increase of 26 patients.
- In 2020 the proportion of patients being treated with palliative intent increased significantly by 11.5% (p=0.001) compared with patients diagnosed in 2019.
- The proportion of patients receiving best supportive care increased in 2020 by 5.5% (26 patients) compared with 2019.
- These changes in treatment plan intent between 2019 and 2020 are statistically significant (p=0.003) and may be due to the increased proportion of patients diagnosed with later stage disease in 2020 (Table 21) and possible changes in treatment protocols during the first wave of the COVID-19 pandemic.

*Figure 17 Proportion of patients with a **curative** treatment plan by pancreatic cancer stage and age group*

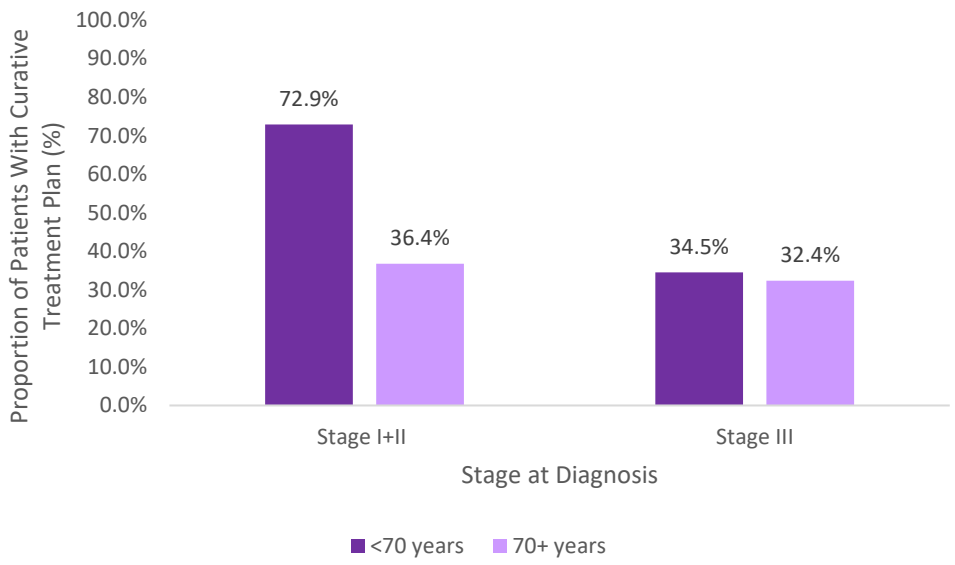


Table 38: Proportion of patients with a curative or palliative treatment plan by tumour stage and age group for pancreatic cancer patients diagnosed 2019-2020, NI

	Stage I+II (n=146)			Stage III (n=66)		
	<70 years (n=59)	70+ years (n=88)	Statistical Significance	<70 years (n=29)	70 + years (n=37)	Statistical Significance
Curative Treatment Plan	43 (72.9%)	32 (36.4%)	P<0.001	10 (34.5%)	12 (32.4%)	P=0.86
Palliative Treatment Plan	16 (27.1%)	56 (63.6%)		19 (65.5%)	25 (67.6%)	

- Figure 17 and Table 38 show early stage (I and II) patients aged over 70 years were significantly less likely (p=<0.0001) to have a curative treatment plan (36.4%) compared with patients younger than 70 (72.9%).
- Approximately one third of stage III tumours are treated with curative intent with no significant differences between those older and younger than 70 years.

Treatment Delivered

*Table 39: Treatment modality **delivered** by original treatment intent at diagnosis for patients diagnosed with pancreatic cancer 2019-2020, NI*

	Treatment Intent		
Treatment Mode	**Palliative n=436 (%)**	**Curative n=104 (%)**	**Total N=540 (%)**
Best Supportive Care	324 (74.3%)	8 (7.7%)	332 (61.5%)
Surgery Only	<5	30 (28.8%)	34 (6.3%)
Surgery + Oncology	<5	50 (48.1%)	53 (9.8%)
Oncology Only	105 (24.1%)	16 (15.4%)	121 (22.4%)

*Figure 18: Treatment modality **delivered** by original treatment intent at diagnosis for patients diagnosed with pancreatic cancer 2019-2020, NI*

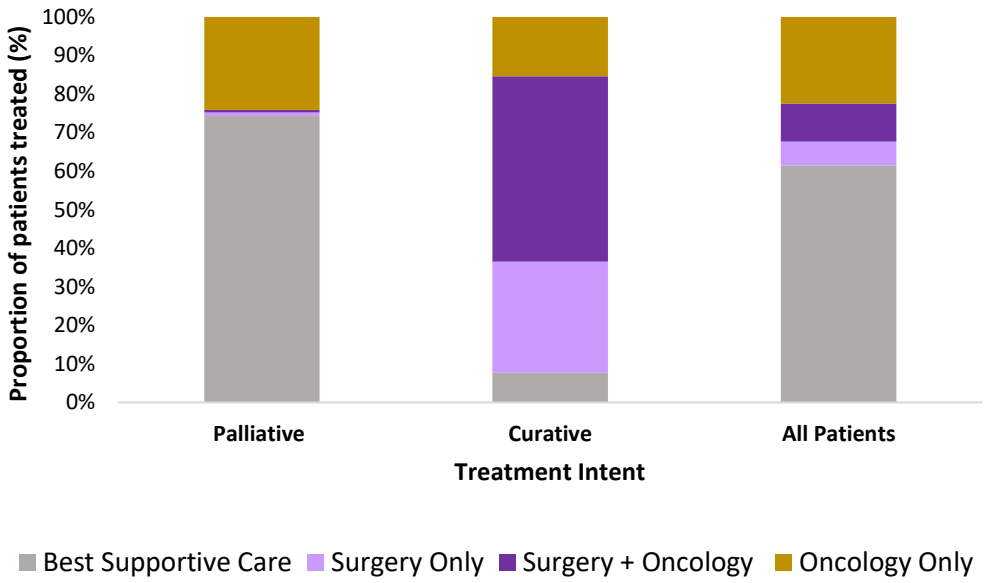


Table 39 and Figure 18 show the treatment modalities delivered to patients by initial treatment intent at diagnosis. Patients categorised as "Best Supportive Care" are likely to have had other therapies to aid symptom control, e.g. pain relief

- Overall, 61.5% of pancreatic cancer patients received best supportive care (BSC) only and did not receive treatment to reduce the tumour. For patients with palliative intent this is higher with 74.3% receiving BSC only compared to 7.7% who received a curative plan.
- Table 37 and Table 39 show there were 232 patients with plans for BSC at MDT. However, the number of palliative patients who received BSC by the end of 2021 was much higher at 324. This could be due to patient choice or disease advancement in these 92 patients (17% of all 540 patients).
- The main mode of tumour reducing treatment for palliative patients was oncology with about a quarter having this treatment, with 24.1% having oncology only and 0.7% having oncology in combination with surgery.
- 76.9% of curative patients have surgical resection as their main mode of treatment with 48.1% having surgery in combination with oncology (Table 39).

Treatment Timelines

Table 40: Median wait times (in days) from referral to first treatment, by treatment type and treatment intent for pancreatic cancer patients diagnosed 2019-2020, NI

		Diagnosis to First Treatment			Referral to First Treatment		
First Treatment Type	**Year of diagnosis**	**Total number in analysis**	**Median**	**IQR p25-75**	**Total number in analysis**	**Median**	**IQR p25-75**
Curative Surgery 1st Treatment	**2019**	n=47	11 days	0-47 days	n=44*	60 days	33-118 days
	2020	n=23	30 days	0-49 days	n=23	59 days	41-99 days
Curative definitive or neo-adjuvant oncology	**2019**	n=12	49 days	35-50 days	n=12	72 days	57-92 days
	2020	n=14	62 days	42-83 days	n=14	79 days	61-104 days
Palliative Oncology	**2019**	n=49	44 days	35-69 days	n=49	68 days	53-97 days
	2020	n=56	43 days	34-53 days	n=56	65 days	54-84 days

IQR p25-75: Interquartile range 25%-75%*

Note: 3 patients were excluded from this analysis due missing date of referral on CaPPS. NICR date of diagnosis is derived using international guidelines to ensure global standardisation of cancer survival data. Surgical patients' date of diagnosis can often be the date of microscopic verification as it is considered the highest standard of diagnosis for pancreatic cancer. Therefore, decision to treat can be based on scans prior to the official date of diagnosis, and the date of first treatment can be the date of surgery itself.

- Median wait from diagnosis to first treatment in 2020 was 19 days longer than in 2019 for patients who had a curative surgery as their first treatment, which may be due to the impact of COVID-19. However, patients in 2020 had a shorter median time from referral to treatment (1 day), which is likely due to staging investigations being quicker compared to 2019 (Table 30 & Table 31)
- Curative patients who have oncology as 1st treatment have the longest referral to treatment wait times with patients waiting a median 72.5 days in 2019 and 79 days in 2020. This may be due to delays in staging invitations required for curative oncology regimes during the early stage of the COVID 19 pandemic in 2020. Note small numbers in analysis n=26.
- Palliative oncology patients had a slightly shorter time from diagnosis to 1st treatment and referral to first treatment in 2020 in comparison to 2019. This is despite more patients being treated with palliative oncology in 2020. Table 37

Surgery

87 patients had surgical resection representing 16.1% of all pancreatic cancer patients (Table 41). There was a significant reduction (p=0.003) in the proportion of patients who received surgery in 2020 (11.7%) compared to 2019 (21%).

Table 41: Proportion of patients who received pancreatic cancer surgery, 2019-2020

Surgery	2019 n=257 (%)	2020 n=283 (%)	Total n=540 (%)
Yes	54 (21.0%)	33 (11.7%)	87 (16.1%)
No	203 (79.0%)	250 (88.3%)	453 (83.9%)

Table 42 shows that patients with malignant (NET) are more likely to receive surgery compared with patients with adenocarcinoma & carcinoma NOS tumours (47.1% v 14.0%).

Table 42: The proportion of patients who receive pancreatic cancer surgery for patients diagnosed 2019-2020 by histological subtype

Surgery	Adenocarcinoma & Carcinoma NOS n=506 (%)	Malignant Neuroendocrine Tumours n=34 (%)	Total n=540 (%)
Yes	71 (14.0%)	16 (47.1%)	87 (16.1%)
No	435 (86.0%)	18 (52.9%)	453 (83.9%)

Table 43 shows the majority of patients who had curative surgery with the intention of reducing tumour load had a Whipple's resection (57.5%). Other surgeries included open tumour excision (not otherwise specified), attempted surgeries that could not be completed due to contraindications during surgery and procedures to reduce symptoms.

Table 43: Type of pancreatic cancer surgery for patients diagnosed 2019-2020, NI

Surgery Type	Number of patients resected n=87 (%)
Whipple's	50 (57.5%)
Total Pancreatectomy	21 (24.1%)
Other	16 (18.4%)

Table 44 shows the majority of patients who under-go surgery have open surgery (85.1%). Laparoscopic surgery is mainly suitable for resection of the distal pancreas. This audit did not collect data on surgical location (i.e. distal or proximal).

Table 44: Access type for completely resected pancreatic tumours for patients diagnosed 2019-2020, NI

Surgical Access Type	Proportion of patients with complete tumour resection (n=87)
Open Surgery	74 (85.1%)
Laparoscopic	12 (13.8%)
Not Known	1 (1.1%)

Tumour-Margin Status

Table 45: Complete resection status of pancreatic cancer patients diagnosed 2019-2020 who underwent surgery

Complete resection	Total n=87 (%)
Yes	72 (82.8%)

During 2019-2020 82.8% (72/87) of surgical patients had their full tumour excised. Reasons for non-complete tumour removal include contraindications to full resection during surgery.

Table 46: Tumour margin status for fully excised tumours of pancreatic cancer patients diagnosed 2019-2020 who underwent surgery

	Proportion of patients with negative margins
Superior Mesenteric Vein (SMV) Surface Margin (n=70)*	44 (62.8%)
Superior Mesenteric Artery (SMA) Margin (n=70)*	50 (71.4%)
Anterior (n=72)	61 (84.7%)
Posterior (n=72)	54 (75.0%)
R0- Complete clear margins (n=72)	20 (27.8%)
R1- Microscopic Residual Disease (n=72)	52 (72.2%)

**Note: the superior mesenteric vein surface margin and superior mesentery artery surface margins' denominator have been adjusted for patients who underwent a complete resection via a Whipple's procedure or total pancreatectomy.*

- 27.8% of patients with complete resection had microscopically clear margins in all directions.
- The anterior margin is most likely to be free of microscopic disease (84.7%), while the SMV is least likely (62.8%).

Hospital of Surgery

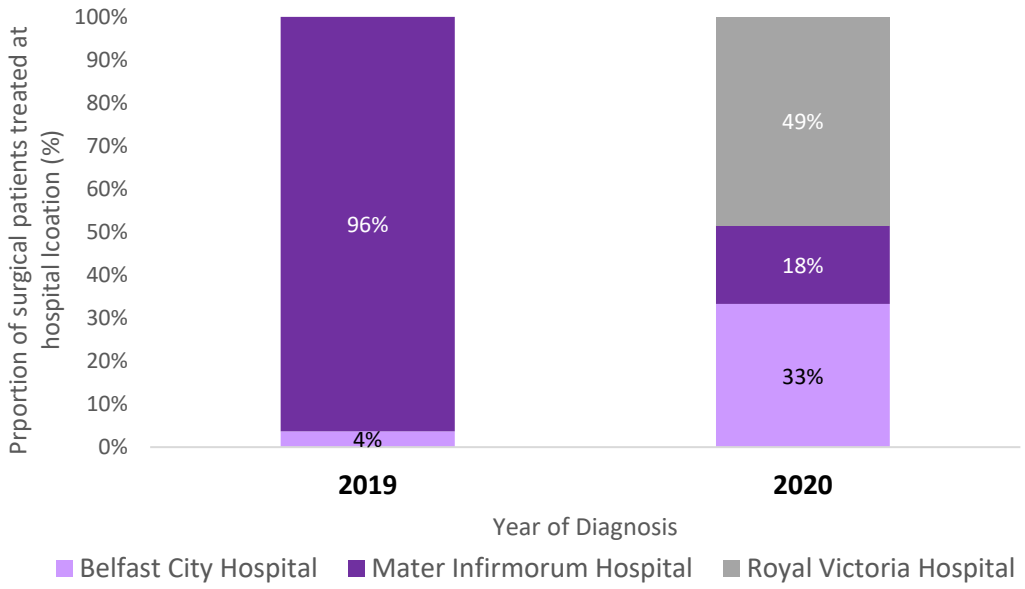
Table 47: Hospital of surgery for pancreatic cancer patients diagnosed 2019-2020 who underwent surgery, NI

	2019 n=54 (%)	2020 n=33 (%)	Total n=87 (%)
Belfast City Hospital (BCH)	2 (3.7%)	11 (33.3%)	13 (14.9%)
Mater Hospital (MIH) *	52 (96.3%)	6 (18.2%)	58 (67.7%)
Royal Victoria Hospital (RVH)	0 (0.0%)	16 (48.5%)	16 (18.4%)

**(Includes n=<5 Other setting)*

- A small, centralised team provides surgical care for pancreatic cancer patients with 4 surgeons in 2019 and 5 in 2020.
- In 2019 a centralised surgical unit at MIH performed the vast majority of surgeries (96.3%).
- During the first year of the COVID-19 pandemic in 2020 pancreatic surgery services were re-organised and spread across three Belfast HSC Trust hospitals, and RVH became the main surgical site with 48.5% of operations performed there.
- As of January 2023 surgical services have been centralised again, now based at one unit in BCH.

Figure 19: Hospital of surgery for pancreatic cancer patients diagnosed 2019-2020 who underwent surgery, NI



Post-Operative Complication and Length of stay

As shown in Table 48, just over a quarter (28.7%) of patients who had surgery developed post-operative complications. Post-operative complication status was determined by the pancreatic surgical team on review of clinical notes and were defined as a medical condition arising as a consequence of the operation. Specific post-operative complications were too low in number to analyse. The low post-operative complication rate suggests good pre-operative patient selection and intra and post operative care and management.

Table 48: Post-operative complication rate by year of diagnosis

	2019 n=54 (%)	2020 n=33 (%)	Total n=87 (%)
Post-operative complication occurred	16 (29.6%)	9 (27.3%)	25 (28.7%)
No post-operative complication	38 (70.4%)	24 (72.7%)	62 (71.3%)

Table 49 shows the median length of stay for surgical pancreatic cancer patients was 11 days for both 2019 and 2020.

Table 49: Hospital length of stay following surgery for pancreatic cancer patients diagnosed 2019-2020, NI

2019 n=54		2020 n=32*		Total n=86*	
Median days	Interquartile range	Median days	Interquartile range	Median days	Interquartile range
11 days	8-17 days	11 days	9.5-16 days	11 days	9-17 days

**Note there was one case with dates were admin/discharge that were not valid for analysis*

Table 50: Hospital length of stay following surgery by post-operative complication status for pancreatic cancer patients diagnosed 2019-2020, NI

	Median Length of Stay	Median Length of Stay IQR**
Post-operative complication (n=25)	15 days	11-21 days
No post-operative complication (n=61*)	10 days	8-14 days

**Note there was one case were admin/discharge that were not valid for analysis*
*** IQR=Inter-quartile Range*

- As expected, patients with post-operative complications had a longer hospital stay (15 days) than those who did not (10 days).
- Only five (5.7%) surgical patients were readmitted to hospital within 30 days of their surgery, again suggesting good pre-surgical patient selection, intra- and post-operative care and management.

Post-Surgical Mortality

Both 30 and 90-day post-surgical mortality rates were low (Table 51) suggesting appropriate patient selection.

Table 51: 30/90-day mortality following surgery for pancreatic cancer patients diagnosed 2019-2020, NI

	Proportion of surgical patients n=87 (%)
30- Day mortality rate	n<5
90- Day mortality rate	6 (6.9%)

Curative Surgery and Chemotherapy

NICE Guidelines NG85 (2018):

- Offer Gemcitabine plus Capecitabine to adenocarcinoma & carcinoma NOS patients who have had sufficient time to recover from a pancreatic cancer resection.
- Consider adjuvant Gemcitabine for people who are not well enough for combination therapy.

Table 52: Proportion of adenocarcinoma & carcinoma NOS patients with complete resection treated with adjuvant chemotherapy regime post-surgery

Chemotherapy regime	2019/2020 n=37 (%)
Gemcitabine/Capecitabine	19 (51.4%)
Folfirinox	14 (37.8%)
Gemcitabine	n=<5
Capecitabine	n=<5

- 37 patients with complete resection were treated with adjuvant chemotherapy, of which Gemcitabine/Capecitabine was the most common regime received (51.4%).
- No surgical patients with a malignant neuroendocrine tumour received adjuvant chemotherapy.

Table 53: Proportion of adenocarcinoma & carcinoma NOS patients treated with neo-adjuvant chemotherapy who progressed to surgery

	2019/2020 n=28
Neo-adjuvant chemo and surgery	10 (35.7%)
Neo-adjuvant chemo and no surgery	18 (64.3%)

- Table 53 shows the proportion of adenocarcinoma & carcinoma NOS patients initially treated with chemotherapy with the aim of having subsequent surgery. In total 28 patients were treated with this intention representing 5.2% of all pancreatic cancer patients.
- However, 18 (64.3%) of these patients did not proceed to surgery, with reasons including tumour progression, chemotherapy toxicity and death. NICE guidelines NG85 (2018) recommend neo-adjuvant chemotherapy only in clinical trials, however no neoadjuvant patients were entered into a trial with the NI Cancer Trials Centre assessing neoadjuvant chemotherapy with surgery.

Oncology

Table 54: Patients referred to oncology and oncology treatments delivered by audit year

Referred to Oncology?	2019 n=257		2020 n=283		Total n=540	
	Oncology Delivered n=86 (%)	No Oncology n=171 (%)	Oncology Delivered n=88 (%)	No Oncology n=195 (%)	Oncology Delivered n=174 (%)	No Oncology n=366 (%)
Yes (%)	86 (100.0%)	36 (21.1%)	88 (100.0%)	35 (17.9%)	174 (100.0%)	71 (19.4%)
Declined (%)	0 (0.0%)	12 (7.0%)	0 (0.0%)	7 (3.6%)	0 (0.0%)	19 (5.2%)
Not Referred (%)	0 (0.0%)	123 (71.9%)	0 (0.0%)	153 (78.5%)	0 (0.0%)	276 (75.4%)

- Table 54 shows 264 patients were met MDT requirements to be referred to oncology during 2019-2020 of which 174 (65.9%) received oncological therapy (chemotherapy and/or radiotherapy) and 71 (26.8%) did not progress to treatment. Of the 264 patients that met requirements to be referred to oncology, 19 (7.2%) patients declined a referral to oncology.
- The proportion of patients referred to oncology was similar across audit years.

Table 55: Proportion of pancreatic cancer patients who received chemotherapy or radiotherapy by treatment intent

	Curative Intent Plan n=104 (%)	Palliative Plan n=436 (%)	Total n=540 (%)
Chemotherapy (total)	66 (63.5%)	106 (24.3%)	172 (31.9%)
Radiotherapy (total)	13 (12.5%)	17 (3.9%)	30 (5.6%)

- 172 patients (31.9%) during 2019-2020 received chemotherapy as part of their treatment plan compared to only 30 patients (17%) In 2007. This represents an increase of 14.6% in those receiving chemotherapy over this period and translates to an additional 142 patients treated by oncology.
- Radiotherapy was utilised as a treatment modality for 5.6% of patients.
- Note the majority of radiotherapy patients also received chemotherapy.
- A larger proportion of patients with a curative plan were treated with both chemotherapy and radiotherapy compared to those with a palliative plan.

Table 56: Proportion of pancreatic cancer patients receiving chemotherapy by histological subtype

Chemotherapy	Adenocarcinoma & Carcinoma NOS n=504 (%)	Malignant Neuroendocrine Tumours (NET) n=34 (%)	Total n=540 (%)
Yes	166 (32.8%)	6 (17.7%)	172 (31.9%)
No	340 (67.2%)	28 (82.4%)	368 (68.1%)

- 32.8% of Adenocarcinoma & Carcinoma NOS, and 17.7% of Malignant NET patients receive chemotherapy.
- Numbers were too low to analyse radiotherapy treatments by histological subtype.

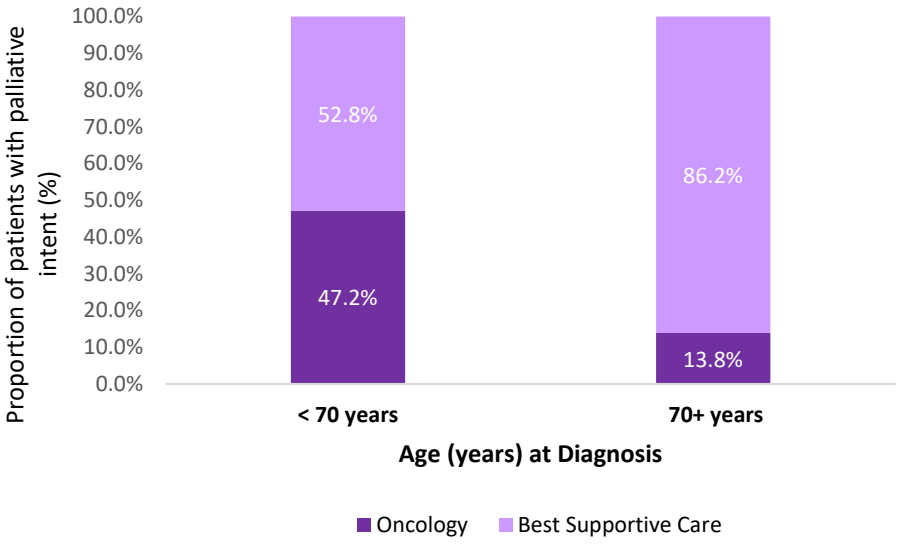
Oncology-Non-Curative Treatment

Table 57: Palliative patients treated with best supportive care or oncology by age group and year of diagnosis

	2019 (n=191)			2020 (n=240)		
Treatment	<70 years (n=70)	70+ years (n=121)	Statistical Significance	<70 years (n=74)	70 + years (n=167)	Statistical Significance
Oncology	33 (47.1%)	17 (14.0%)	P<0.001	35 (47.3%)	23 (13.8%)	P<0.001
Best Supportive Care	37 (52.9%)	104 (86.0%)		39 (52.7%)	144 (86.2%)	

**This analysis excludes 4 palliative patients who had surgical intervention as their only therapy*

Figure 20: Proportion of palliative patients treated with oncology or best supportive care by age group, 2019-2020



**This analysis excludes 4 palliative patients who had palliative surgical intervention as their only therapy*

- The majority of palliative patients are not given tumour reductive therapy, but rather receive best supportive care on their pancreatic care pathway (Table 57, Figure 20).
- Patients under 70 years have a significantly higher proportion undergoing oncology compared with patients over 70 years (47.2% vs 13.8%, p=<0.0001). This could be due to higher rates of comorbidities and differing treatment preference profile in older patients.
- There was no difference across these age groups between patients diagnosed in 2019 and 2020 (Table 57).

Chemotherapy Outcome

Table 58: Outcome of chemotherapy by treatment intent for pancreatic cancer patients diagnosed 2019-2020, NI

	Palliative intent n=106 (%)	Curative intent n=66 (%)	Total n=172 (%)
Chemotherapy delivered as prescribed	28 (26.4%)	30 (45.5%)	58 (33.7%)
Chemotherapy completed not as prescribed	<5	9 (13.6%)	**
Chemotherapy Completion status not known	13 (12.3%)	<5	**
Chemotherapy not completed due to patient choice	7 (6.6%)	<5	**
Chemotherapy not completed due to progression	19 (17.9%)	8 (12.1%)	27 (15.7%)
Chemotherapy not completed due to toxicity	22 (20.8%)	13 (19.7%)	35 (20.3%)
Chemotherapy not completed due to death	10 (9.4%)	<5	**
Chemotherapy not completed - "other" reason	<5	0 (0.0%)	**

*** Supressed due to low numbers*

- Approximately 1/3 of chemotherapy patients finish their prescription as originally prescribed. A higher proportion of curative patients finished their chemotherapy compared with palliative patients.
- Approximately 1/5 of patients did not complete their prescribed chemotherapy regime due to toxicity with palliative and curative patients similarly affected.
- 12.1% of curative patients experienced progression while undergoing chemotherapy and 17.9% of palliative patients stopped chemotherapy due to disease progression.
- 9.4% of palliative patients died during their chemotherapy treatment.

Table 59: 30- and 90-day mortality rates from commencement of chemotherapy for pancreatic cancer patients diagnosed 2019-2020, NI

	Proportion of chemotherapy patients n=172 (%)
30-day mortality rate	8 (4.7%)
90-day mortality rate	21 (12.2%)

- 30-day mortality rate for all chemotherapy patients was 4.7%. 90-day mortality rate was 12.2%

Supportive Care

CNS Support

A Clinical Nurse Specialist provides a patient centred and holistic approach to patients, and families and carers. Acting as a key contact for patients during their diagnosis, treatment and ongoing care, they liaise with other members of the MDT, addressing information needs, signposting to other support services and ensuring appropriate, onward referrals in a timely way.

Nursing support in clinical notes are recorded differently on separate software platforms by Trust and specialism type. Data extraction of nursing support has therefore been challenging using electronic sources and completeness levels of patients undergoing best supportive care is difficult to ascertain.

During 2019-2020 Belfast Trust had been the only Trust with HPB CNS specialist nursing support, in the remaining 4 Trusts pancreatic cancer nursing care was covered by upper-gastro-tract CNS who also cover care for patients with oesophago-gastro cancers.

Table 60: Patients seen by CNS by intent of therapies delivered

	Curative n=104 (%)	Palliative Anti-Cancer n=112 (%)	Best Supportive Care n=324 (%)	Total n=540 (%)
Seen by CNS	99 (95.2%)	103 (92.0%)	155 (47.8%)	357 (66.1%)

- In total, 357 (66.2%) patients were seen by a CNS.
- Patients that received tumour reducing treatments were more likely to receive CNS input than those who did not, with 95.2% of curative patients and 92% of patients treated with palliative anti-cancer regimes having a CNS appointment compared with only 48% of patients who received best supportive care.

Supportive Care for Palliative Patients

Table 61: Palliative patients receiving supportive care by palliative treatment intent

	Palliative Anti-Cancer n=112 (%)	Best Supportive Care n=324 (%)	Total n=436 (%)
CNS	103 (92.0%)	155 (47.8%)	258 (59.2%)
Seen by HPB Specialist nurse	27 (24.1%)	34 (10.5%)	61 (14.0%)
Seen by hospice nurse	49 (43.8%)	124 (38.3%)	173 (39.7%)
Dietician	87 (77.7%)	165 (50.9%)	252 (57.8%)
Information Support	34 (30.4%)	34 (10.5%)	68 (15.6%)
Specialist onward referral made (all):	105 (93.8%)	294 (90.7%)	399 (91.5%)
• Palliative Care Team	67 (59.8%)	205 (63.3%)	272 (62.4%)
• District Nurse	82 (73.2%)	205 (63.3%)	287 (65.8%)
• Social Services	33 (29.5%)	61 (18.8%)	94 (21.6%)
• Occupational Therapy	24 (21.4%)	107 (33.0%)	131 (30.1%)
• Physiotherapy	12 (10.7%)	54 (16.7%)	66 (15.1%)
• Referral to Macmillan	10 (8.9%)	9 (2.8%)	19 (4.4%)

- The low proportion of palliative patients having interaction with a HPB specialist nurse (14%) is likely an under-representation. Nursing support in clinical notes are recorded differently on separate databases by Trust and specialism type. During 2019-2020 Belfast Trust had been the only Trust with HPB specialist nursing support, in the remaining 4 Trusts pancreatic cancer nursing care is covered by upper-gastro-tract CNS who also cover care for patients with oesophago-gastro cancers.
- District nurses are a part of the wider palliative care team in the community providing essential support and care to palliative patients as their key worker with over 4/5 of patients availing of this service.
- 2/5 of palliative patients availed of hospice nurse support, which is a vital resource in managing pain and end of life care. Much of direct end of life care is provided by district nurses in conjunction with family members and hospice nursing staff. Hospice nurses act in a supportive role providing advice for the management of complex symptoms such as pain, nausea and vomiting.
- 252 palliative patients had a referral to a dietician which represents 57.9% of palliative pancreatic cancer patients. A higher proportion of patients undergoing palliative anti-cancer therapies were seen by a dietician than those receiving best supportive care (77.7% vs 51.1%)
- Specialist onward referral can be any referral that can support pancreatic cancer patients. The two biggest categories of specialist onward referrals were to palliative care teams (PCT) (Community and Hospital) and District Nursing with 65.8% and 62.4% of palliative patients referred to these specialities respectively.
- Social services received referrals from approximately 1/5 of patients (21.6%).

Clinical Trials

Table 62: Trial Access at incident diagnosis for pancreatic Cancer patients diagnosed in 2019-2020, NI

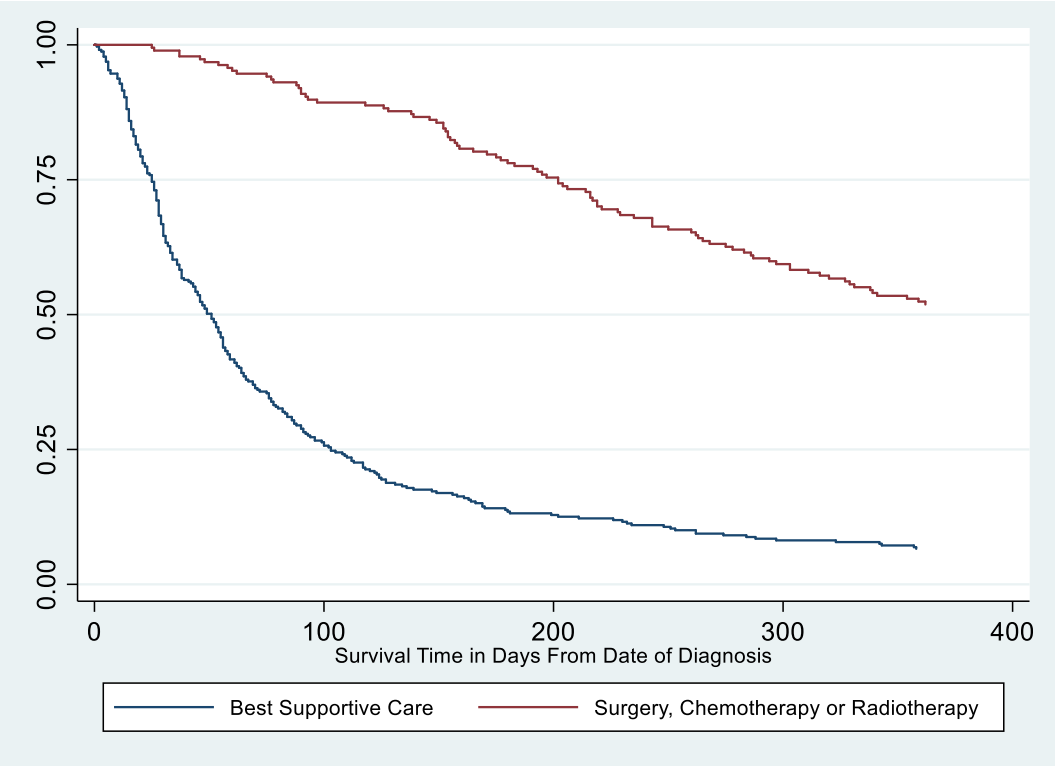
Enrolled in trial during audit period 2019-2020	Number of patients (%) n=540
Enrolled in Trial	5 (0.9%)
Non-Enrolled in Trial	535 (99%)

As shown in Table 62, the number of patients diagnosed 2019-2020 that were enrolled on a trial with the NI Cancer Trials Centre was low at 0.9%.
Between 2018-2021 recruitment was open for pancreatic cancer patients for the following trials in NI:

- Phase 1 trial of LY3143921 hydrate in solid tumours.
- Pioneer Phase 1.
- PrecisionPanc.
- PRIMOUS 001 Phase II.

Survival Analysis

Figure 21: KM Survival for adenocarcinoma & carcinoma NOS pancreatic cancer patients diagnosed 2019-2020 by treatment status



P=<0.0001 Log Rank

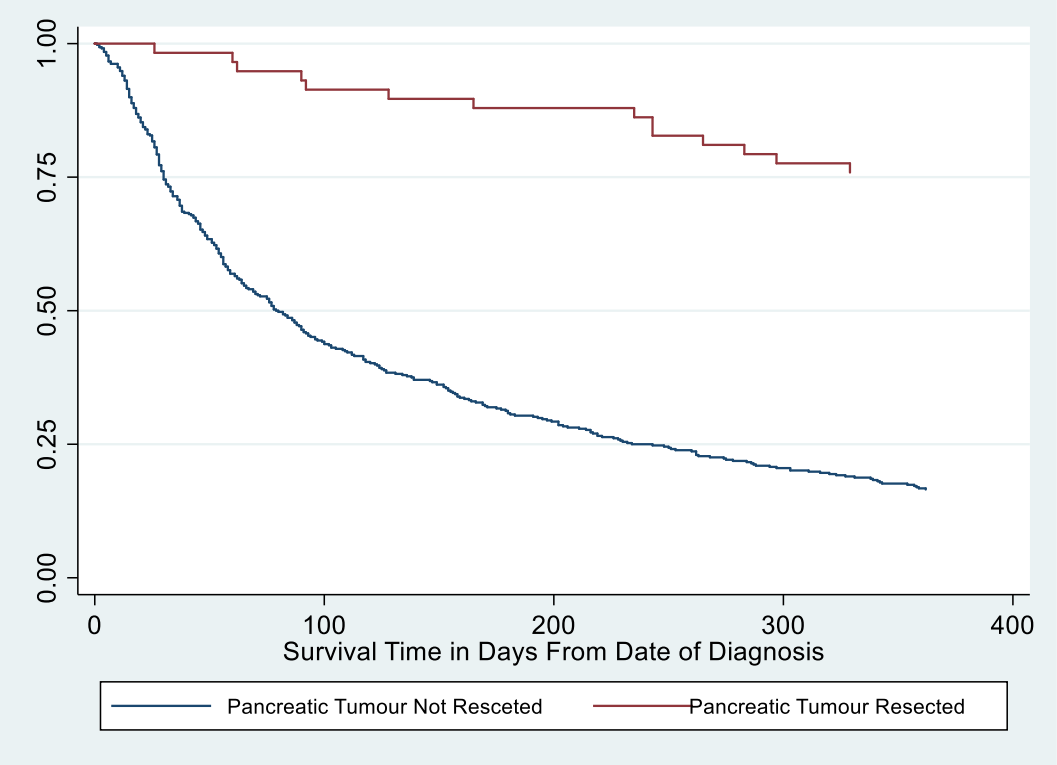
Table 63: Survival for adenocarcinoma & carcinoma NOS pancreatic cancer patients diagnosed 2019-2020 by treatment status and time interval

Treatment Status	Time	Survival (%)
Surgery, Chemotherapy or Radiotherapy	90 days (3 mth)	90.9%
	180 days (6 mth)	78.1%
	365 days (1 year)	51.9%
Best Supportive Care	90 days (3 mth)	28.8%
	180 days (6 mth)	13.5%
	365 days (12 mth)	6.6%

**Note patients with malignant neuroendocrine tumours are excluded from survival analysis*

Table 63 and Figure 21 show patients who receive tumour-reductive treatment (surgery, chemotherapy or radiotherapy) have a significantly better 1-year survival (52% at 1 year) compared to patients receiving BSC (7% at 1 year, p=<0.0001).

Figure 22: KM Survival for adenocarcinoma & carcinoma NOS pancreatic cancer patients diagnosed 2019-2020 by resection status



P=<0.0001 Log Rank

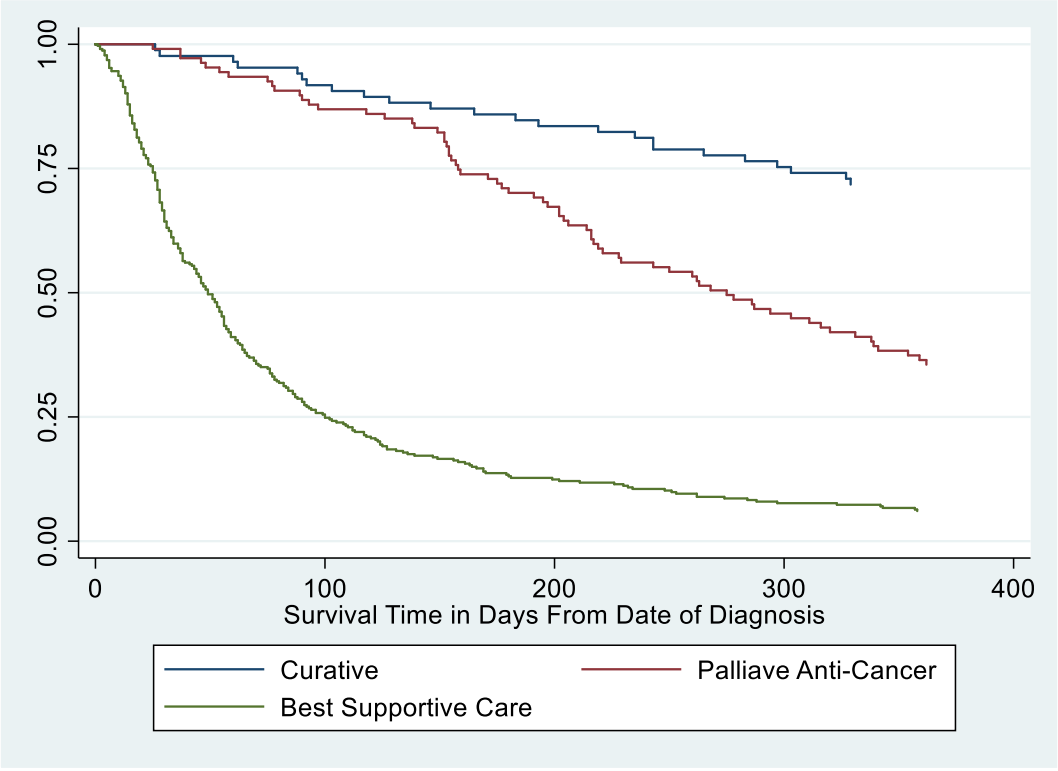
Table 64 Survival for Adenocarcinoma & carcinoma NOS pancreatic cancer patients diagnosed 2019-2020 by resection status and time interval

Resection Status	Time	Survival (%)
Pancreatic Tumour resected	90 days (3 mth)	93.1%
	180 days (6 mth)	87.9%
	365 days (1 year)	75.9%
Pancreatic Tumour not resected	90 days (3 mth)	46.4%
	180 days (6 mth)	30.8%
	365 days (12 mth)	16.5%

**Note patients with malignant neuroendocrine tumours are excluded from survival analysis*

Table 64 and Figure 22 show patients who had pancreatic tumour resection have significantly better 1-year survival (76% at 1 year) compared to patients who did not undergo surgery or have their tumour resected. (17% at 1 year, p=<0.0001).

Figure 23: KM Survival for adenocarcinoma & carcinoma NOS pancreatic cancer patients diagnosed 2019-2020 by treatment plan received



P=<0.00001 Log Rank

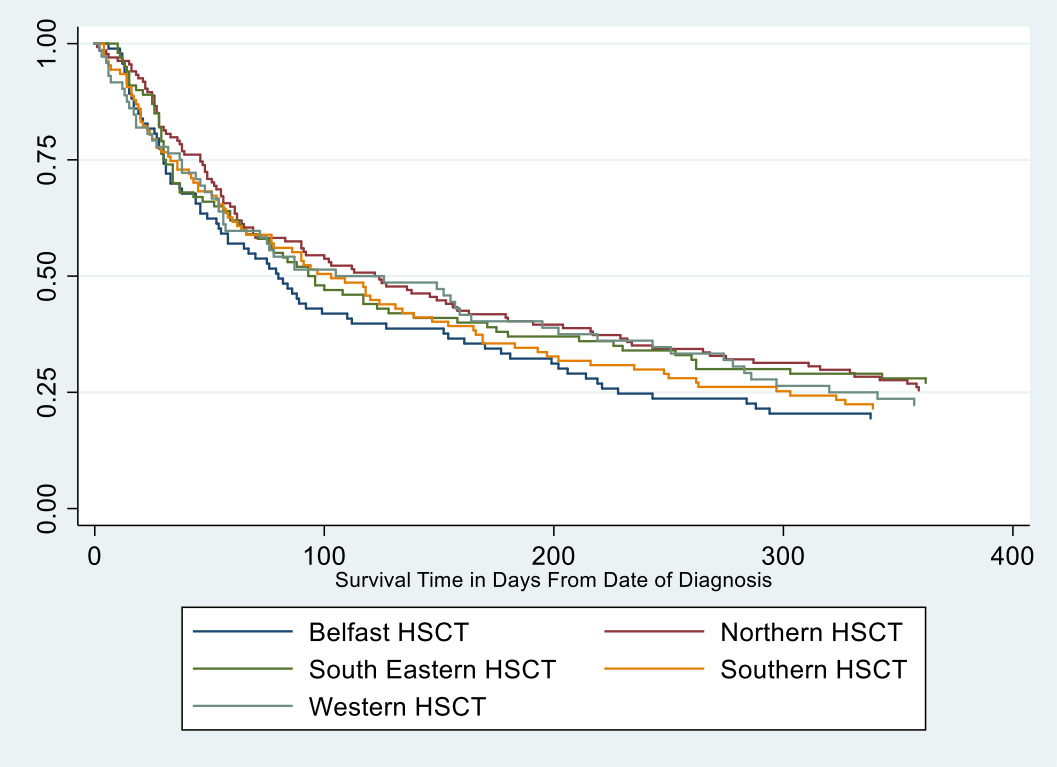
Table 65: Survival for adenocarcinoma & carcinoma NOS pancreatic cancer patients diagnosed 2019-2020 by treatment plan received and time interval

Treatment Plan received	Time	Survival (%)
Curative	90 days (3 mth)	92.9%
	180 days (6 mth)	85.9%
	365 days (1 year)	71.8%
Palliative Anti-Cancer	90 days (3 mth)	88.8%
	180 days (6 mth)	70.1%
	365 days (12 mth)	35.5%
Best Supportive Care	90 days (3 mth)	28.0%
	180 days (6 mth)	13.1%
	365 days (12 mth)	6.1%

**Note patients with malignant neuroendocrine tumours are excluded from survival analysis.*

Table 65 and Figure 23 show differences in survival by the treatment plan a patient received. Curative patients had the highest 1-year survival rate (72%), followed by palliative anti-cancer patients (36%), with patients that received BSC having the lowest survival 1 year-rate of only 6%. These differences are statistically significant (p=<0.001).

Figure 24: KM Survival for adenocarcinoma & carcinoma NOS pancreatic cancer patients diagnosed 2019-2020 by patients' HC Trust of Residence



P=0.8844 Log Rank

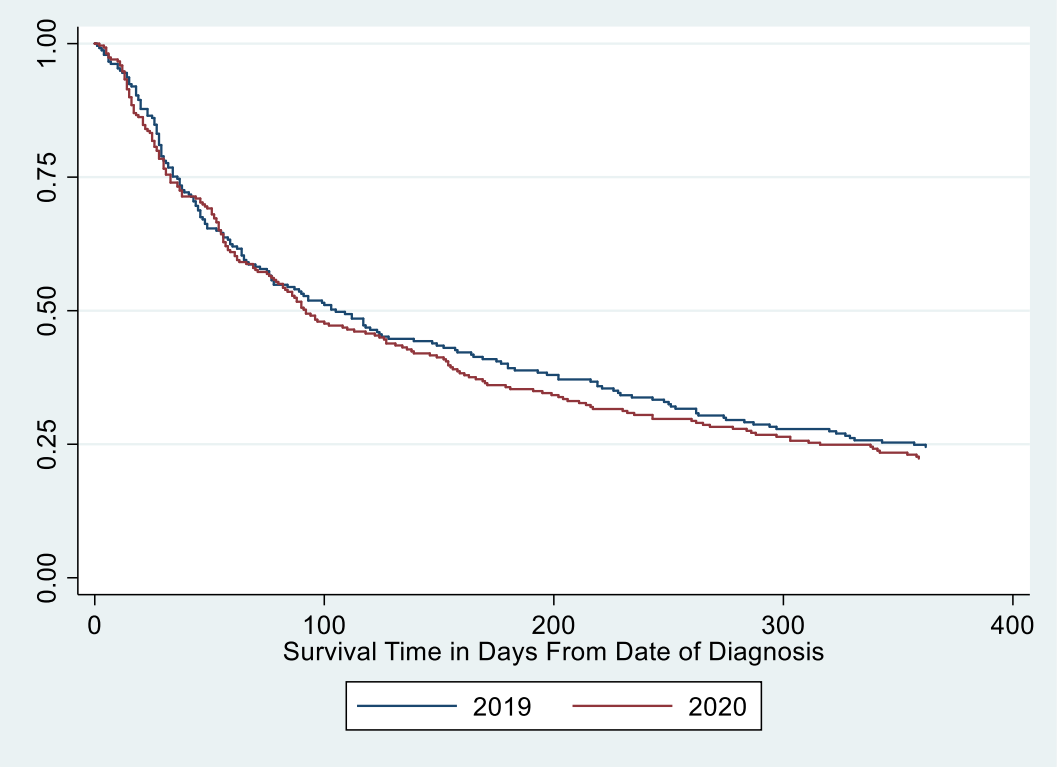
Table 66: One year survival for adenocarcinoma & carcinoma NOS pancreatic cancer patients diagnosed 2019-2020 by patients' HSC Trust of residence, NI

Trust of Residence (By Postcode)	Survival (%)
Belfast HSCT	19.4%
Northern HSCT	25.4%
South-Eastern HSCT	27.0%
Southern HSCT	21.5%
Western HSCT	22.2%

**Note patients with malignant neuroendocrine tumours are excluded from survival analysis*

Figure 24 and Table 66 show that differences in one-year survival by Trust of residence were not statistically significant (p=0.82).

Figure 25: KM Survival for adenocarcinoma & carcinoma NOS pancreatic cancer patients diagnosed 2019-2020 by year of diagnosis



P=0.5657 Log Rank

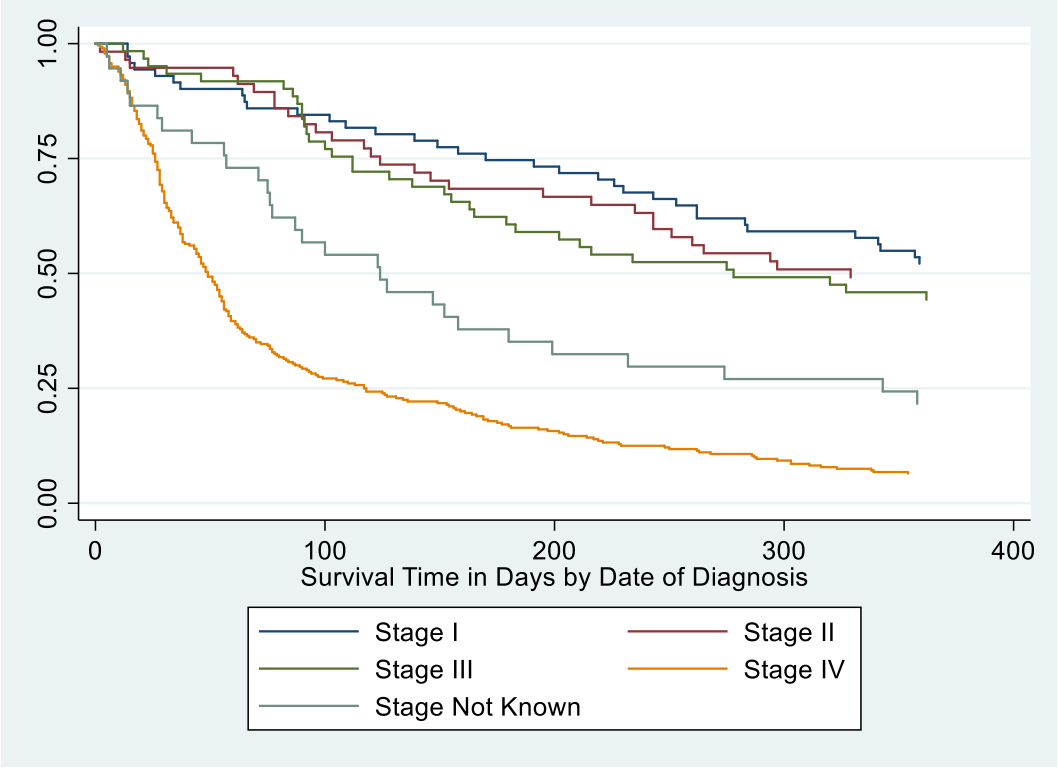
Table 67: Survival for adenocarcinoma & carcinoma NOS pancreatic cancer patients diagnosed 2019-2020 by year of diagnosis

Year of Diagnosis	Time	Survival (%)
2019	90 days (3 mth)	53.2%
	180 days (6 mth)	39.2%
	365 days (12 mth)	24.5%
2020	90 days (3 mth)	50.6%
	180 days (6 mth)	35.7%
	365 days (12 mth)	22.3%

**Note patients with malignant neuroendocrine tumours are excluded from survival analysis*

There was no significant difference in one-year survival rates between 2019 and 2020 (p=0.57) (Table 67 and Figure 25).

Figure 26: KM Survival for adenocarcinoma & carcinoma NOS pancreatic cancer patients diagnosed 2019-2020 by stage



Log rank P=<0.0001

Table 68: One-year survival for adenocarcinoma & carcinoma NOS pancreatic cancer patients diagnosed 2019-2020 by stage

Stage at Diagnosis	2019 Survival (%)	2020 Survival (%)	Total Survival (%)
Stage I	57.6%	47.4%	52.1%
Stage II	40.0%	56.3%	49.1%
Stage III	48.6%	38.5%	44.3%
Stage IV	5.6%	7.1%	6.4%
Stage Not Known	26.3%	16.7%	21.6%

Table 68 and Figure 26 show that one-year survival was progressively and significantly worse with advancing stage of disease, ranging from 52% for Stage I to only 6% for Stage IV (p<0.0001).

Summary and Recommendations

Key Findings	Recommendations
Patient Demographics and Co-morbidities	
There has been an 86% rise in the number of pancreatic cancer patients between the first pancreatic audit in 2001 and 2020 (152 patients in 2001 compared with 283 in 2020, Table 3, Figure 4).	Pancreatic cancer services should be appropriately funded to manage increased patient numbers. Primary prevention and health promotion campaigns, including reducing obesity and increasing physical activity, should be continued and developed.
Family history was not recorded in 3/5 of patient records. (Table 13)	Clinical staff should be supported to allow recording of family history in patient's electronic records.
4.6% of pancreatic cancer patients do not have a CaPPS record. (Table 8)	For audit and research purposes NICR records to be used to ensure complete coverage. Clinical staff should be supported to record details on CaPPS.
Approximately half of pancreatic cancer patients report being current or previous smokers and alcohol drinkers. (Tables 11 and 12)	As a part of holistic care ensure patients are referred to support services such as smoking cessation. Primary prevention and health promotion campaigns to increase awareness of pancreatic cancer risk factors including smoking, alcohol and chronic pancreatitis
There are high levels of multi-morbidity in Pancreatic cancer patients. (Table 17)	Further research is needed to examine pancreatic cancer treatments by patient age group, stage and co-morbidity.
Patients over 70 years are less likely to have a curative treatment plan for early-stage cancers. (Table 38, Figure 17)	Prospective collection of Clinical Frailty Score may allow comparison of treatment by age to support equitable access to treatment for all ages (British Geriatric Society, 2023).

Referral & MDT	
The majority of pancreatic cancer patients are symptomatic at presentation (Table 19, Figure 8). However, the most common route to diagnosis remains via emergency admission (Table 22). Patients seen electively are more likely to have localised stage I-III disease. (Table 23)	PHA, DOH and wider stakeholder groups to work to increase awareness of pancreatic cancer symptoms among the public and GPs.
The majority of pancreatic cancer patients present with distant disease stage IV (Table 20). Diagnosing pancreatic cancer at an earlier stage has a major impact on prognosis, with 1 year survival of 52% for stage 1 compared to only 6% for stage IV patients. (Table 68, Figure 26)	Early diagnosis is key. Health agencies and wider stakeholder groups to work together to seek to increase early diagnosis.
Pancreatic cancer incidence has increased by 85.5% over 19 years since the first 2001 audit. (Table 3, Figure 4). Despite increasing incidence, a high proportion (99%) of patients are discussed at MDT before commencing treatment regimens (p32).	Continue to support MDTs and to use projected trends to estimating future requirements. (NICR, 2023)
1/3 of patients having a diagnosis of anxiety, depression and psychosis. (Table 14)	Personalised and holistic care should be provided.
High levels of Supportive care referrals were reported. (Table 61)	Personalised and holistic care should be provided.
Staging Investigations	
Since 2001 there has been an 124% increase in the number of CT scans for pancreatic cancer. While the majority of patients receive a CT (98.8-97.8%), not all receive a pancreatic cancer protocol CT (Tables 25-26) with approximately 3 in 4 patients getting a CT of chest, abdomen and pelvis.	Future trends of pancreatic cancer should be used to estimate to access future radiology capacity requirements. (NICR, 2023) Patients should have access to and receive appropriate radiological investigation. Increase the proportion of patients having a staging CT scans of chest, abdomen and pelvis as per NICE Guidance.
There was an increase in proportion of patients receiving PET scans in 2020 compared with 2019, likely due to recent commissioning of PET scanning for staging investigations (Table 27).	Future audit required to access the proportion of curative stage I-III patients who receive tumour reductive treatment have a PET scan as per NICE guidance.

Patients who are being considered for surgery or neoadjuvant chemotherapy often have PET-CT or EUS as a part of their staging work-up. During 2019-2020 patients who received these investigations waited 44 days (PET-CT) and 29 days (EUS) for their staging investigations from initial referral. (Table 30).	HPB team to work closely with radiology to ensure more timely access to PET-CT and EUS. This will aid quicker referral to 1st treatment and help to achieve the 62-day target.
Approximately one quarter of all pancreatic cancer patients had suspected liver metastasis at diagnosis. (Table 28) Common metastatic sites for pancreatic cancer during 2019-202 were liver (76%), followed by lung (27.2%), distant nodes, peritoneum, adrenal gland and bone. (Table 33, Figure 15)	HPB team and radiology to ensure timely access to MRI and laparoscopy for patients with suspected liver metastasis as per NICE Guidance. (Table 29)
Rates of microscopically verified (MV) pancreatic cancer have increased over time. Microscopic verification is considered the most accurate method of diagnosing cancer patients. (Table 32, Figure 14)	
Treatment Plan	
Approximately 4 in 5 patients had a treatment plan with palliative intent. This varied by pancreatic cancer histological type with the majority of adenocarcinoma & carcinoma NOS patients treated with palliative intent (83.2%) and the majority of patients with a malignant neuroendocrine tumour treated with curative intent (55.9%). (Table 37, Figure 16)	Further research is required to better understand the effectiveness of patient selection for curative and palliative treatment Future work should compare with the England/Wales audit. (HQIP, 2023)
Patients with a curative treatment plan were more likely to receive tumour-reductive therapies with surgery being the most common curative treatment type (77%). (Table 40)	
Patients with a palliative treatment plan were less likely to receive tumour reducing therapy, and more likely to receive best supportive care (74.3%). (Table 39, Figure 18)	Prospective collection of Clinical Frailty Score may allow comparison of treatments to ensure more equitable access to treatments (British Geriatric Society, 2023).
Patients treated with surgery, chemotherapy, or radiotherapy had much better 1 year survival	Prospective collection of best supportive care data by patient choice, disease severity and symptoms such as fatigue and cachexia to

51.9% compared with patients receiving best supportive care only 6.6%. (Table 63, Figure 22)	better understand patients who receive this treatment plan.
Treatment Waiting Times	
Curative patients who have surgery as their first treatment have the shortest wait for tumour reductive therapy with patients waiting a median 59-60 days from referral to HPB Team. (Table 40) Curative patients receiving neoadjuvant oncology plus surgery have the longest wait from referral to treatment, a median 72-79 days. (Table 40) Palliative oncology patients median wait was 65-68days from referral to oncology. (Table 40)	HPB teams to work with oncology and radiology to reduce staging investigation times and reduce referral to 1st oncology treatment time.
Surgery	
Prior to the COVID 19 pandemic surgery was centralised at one site. During 2020 these changes and surgeries were spread across three sites to include the Royal Victoria and Belfast City hospitals. (Table 47, Figure 19) Only 28% of surgical patients with a complete resection had microscopically clear margins in all direction, with this due to the close proximity of the pancreas to other structures. (Table 46) Post operative complication rate for pancreatic surgery during 2019-2020 is 29%. (Table 48) Median inpatient stay was 11 days. (Table 49) Patients without post-op complications had an inpatient stay of 10 days and patients with a post operative complication had a median inpatient stay of 15 days. (Table 50) Low (6%) 30-day re-admission rate post-surgery (p51) and low post surgical mortality rate shows good patient selection. (Table 51)	Multidisciplinary team involvement may ensure optimisation of care and appropriate selection of patient's pre-operation. Clinicians to undertake review into the benefit of prehabilitation, on post-surgical outcomes to include impact on inpatient stay. (Tay, 2022)

Oncology	
35.7% of curative patients who undergo neoadjuvant oncology manage to have their planned surgery after three cycles. (Table 53)	
A significantly higher proportion of patients under 70 years underwent oncology compared with patients over 70 years (Figure 20 , 47.2%, vs. 13.8%), which could be due to higher rates of comorbidities in older patients and patient choice. (Table 57, Table 14)	Prospective collection of Clinical Frailty Score may allow comparison of treatments by age to ensure more equitable access to treatments (British Geriatric Society, 2023).
Approximately 1/3 of chemotherapy patients finish their prescription as planned. Curative patients have a higher proportion of patients finishing their chemotherapy compared with palliative patients. (Table 58)	
Supportive Care	
The two biggest categories of specialist onward referrals were to the palliative care team and district nurse which cared for 65.8% and 62.4% of all palliative patients. (Table 61)	Appropriate investment in supportive care services is required.
Improve recording of HPB nursing and CNS care on electronic systems to allow analysis of equity of care and audit.	HPB clinical team to review administrative support for CNS service. This should include assessment of ENCOMPASS's future functions to determine if a streamlined regional database for CNS data is possible. This database could facilitate audit, assessment of equity of access to CNS support and continual service development.
Social services receive referrals from approximately 1/5 of patients (21.6%). (Table 61)	
2/5 of palliative pancreatic cancer patients avail of hospice nurse support. This is a vital resource in managing pain and end of life care for patients. (Table 61)	
Clinical Trials	
Clinical trial recruitment for incident pancreatic cancer patients is low 0.9%. (Table 62)	A review to be undertaken by HPB clinical cancer team to encourage better access to trials for pancreatic cancer patients.

	Current clinical trials open to pancreatic cancer patients to be highlighted at each regional MDT with suitability for trials to be actively discussed.

Glossary

Term	*Explanation*
Adjuvant treatment	An additional therapy (e.g. chemotherapy or radiotherapy) provided to improve the effectiveness of the primary treatment (e.g. surgery).
Biliary Bypass	Surgery done to help relieve symptoms caused by a blocked bile duct. During a biliary bypass, the gallbladder or a part of the bile duct before the blockage is connected to either a part of the bile duct that is past the blockage or to the small intestine. This allows bile (fluid made by the liver) to flow around the blockage to the gallbladder or small intestine. A blocked bile duct may be caused by cancer or other conditions, such as gallstones, infection, or scar tissue.
Biliary Stent	Biliary stenting refers to the insertion of stents which are tubes made of plastic or metal to relieve obstruction in the biliary tree or to treat biliary leaks, this is usually done during ERCP or PTC. It can be used to relieve obstruction for both benign and malignant conditions of the biliary tract, while also being used for palliative treatment of advanced malignancies of the biliary tract.
Cachexia	A complex syndrome associated with an underlying illness, causing ongoing muscle loss that is not entirely reversed with nutritional supplementation. In contrast to weight loss from inadequate caloric intake, cachexia causes mostly muscle loss instead of fat loss. Diagnosis of cachexia can be difficult due to the lack of well-established diagnostic criteria. Cachexia can improve with treatment of the underlying illness, but other treatment approaches have limited benefit. Cachexia is associated with increased mortality and poor quality of life.
Chemotherapy	Drug therapy used to treat cancer. It may be used alone, or in conjunction with other types of treatment (e.g. surgery or radiotherapy).
Clinical Nurse Specialists (CNS)	These are experienced, senior nurses who have undergone specialist training. They play an essential role in improving communication with a cancer patient, being a first point of contact for the patient and coordinating the patient's treatment. HPB CNS/nurse specialises in Pancreatic, Liver and Biliary cancers.
Comorbidity	Describes the existence of more than one disease or condition within the body at the same time. Comorbidities are usually long-term, or chronic. They may or may not interact with each other.
Computed Tomography (CT) scan	An imaging modality that uses X-ray radiation to build up a 3- dimensional image of the body.
Curative care	This is where the aim of the treatment is to cure the patient of the disease.
Diabetes (Diabetes mellitus)	A group of metabolic diseases in which a person has high blood sugar, because the body does not produce enough insulin or because the cells to do not react to the insulin that is produced. It is also known as diabetes mellitus.
Distal Pancreatectomy	This is the removal of the tail of the pancreas but leaving the head neck and proximal part of the body. The spleen may be removed at the same time as the tail, because the pancreas is next to the spleen.

Duodenal Stent	Pancreatic cancer can block the top of the small bowel (duodenum). A stent (which are tubes made of plastic or metal) may be inserted to keep the duodenum open and relieve symptoms.
Endoluminal Ultrasound Scan (EUS)	This is valuable in the detection of early pancreatic tumours which can be as small as 2-3mm EUS is carried out by passing a thin flexible telescope (endoscope) with a probe attached through the mouth and into the stomach which takes images of the pancreas and the surrounding areas.
Endoscopic Retrograde Cholangiopancreatography (ERCP)	A thin flexible telescope (endoscope) is passed through the mouth into the stomach and a special dye is injected into the bile and pancreatic ducts. An x-ray will be taken, and this will outline any tumour that is blocking the bile and pancreatic duct. During the procedure a small brush can be pushed into the ducts and any cells can then be examined to see if they are cancerous.
Endoscopic stent	A medical procedure by which a stent, a hollow device made of plastic or metal, designed to prevent constriction or collapse of a tubular organ, is inserted by endoscopy. They are usually inserted when a disease process has led to narrowing or obstruction of the organ in question.
Jaundice	Jaundice is when a person's skin and the whites of the eyes are discoloured yellow. This is due to an increased level of bile salts in the blood and is a symptom caused by various diseases which disrupt the processing and transport of bile.
Laparoscopic surgery	This is a surgical technique (also called minimally invasive or keyhole surgery) where the surgeon accesses the inside of the body without having to make the large skin incisions used in open surgery. To do this, they use an instrument called a laparoscope (which contains a camera and light source) along with other specialised equipment which can be inserted through several small skin incisions. In general, patients who have laparoscopic surgery have a shorter hospital stay and faster recovery time.
Lymph nodes	Lymph nodes are small bean shaped organs, often also referred to as lymph 'glands', which form part of the immune system. They are distributed throughout the body and can be one of the first places to which cancers spread.
Magnetic Resonance Cholangiopancreatography (MRCP)	A technique used to visualise the biliary tract and pancreatic ducts using a powerful magnetic field and radio frequency pulses which produce a detailed picture of the internal body organs. The images are then sent to a computer monitor to be viewed to see if the pancreas contains a tumour.
Magnetic resonance imaging (MRI)	A type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.
Metastasis	Spread of cancer away from the original site to form deposits elsewhere in the body, usually via the bloodstream or the lymphatic system. The deposits may be referred to as metastases, metastatic deposits or secondary cancers.
Microscopic verification	A sample of tissue is taken and examined under a microscope to confirm the type of cancer cells present.
Multi-disciplinary team (MDT)	A group of professionals from diverse specialties that works to optimise diagnosis and treatment throughout the patient pathway.
National Institute of Health and Clinical Excellence (NICE)	An independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

Neo-adjuvant treatment	Chemotherapy (and/or radiotherapy) treatment for cancer to improve the effectiveness of another treatment, usually surgery. Neo-adjuvant therapy is given prior to the other treatment (surgery). This is usually given to reduce the size, grade or stage of the cancer and therefore improve the effectiveness of the surgery performed.
Non-curative anti-cancer treatment	A non-curative treatment is for prolonging life and reducing symptoms. It is often given to patients with advanced cancer to make them more comfortable towards the end of life.
Palliative care	The care given to patients whose disease cannot be cured. It aims to improve quality of life rather than extend survival and concentrates on relieving physical and psychological distress.
Palpable mass	A tumour that can be felt by hand during a physical examination.
Pancreatic exocrine insufficiency	When the pancreas is healthy, it produces several enzymes, which are a group of proteins that work as catalysts in digestion. It secretes these enzymes into the small intestine where they work to help digest food. These different enzymes digest carbohydrates (amylase), proteins (proteases including trypsin and chymotrypsin), and fats (lipase). In individuals with pancreatic exocrine insufficiency (PEI), the pancreas doesn't make enough of these enzymes to adequately break down food into absorbable components. This can lead to serious nutritional deficiencies, and the symptoms these deficiencies cause.
Pancreatitis	Pancreatitis is the persistent inflammation of the pancreas – amongst other causes alcohol consumption over long periods of time is one of the most common causes. There are two types of pancreatitis acute & chronic. People who have chronic pancreatitis are more likely to develop pancreatic cancer and it is diagnosed in about one in 100,000 people in the UK each year.
Patient Journey	A technical term used within the NHS to describe the various stages that an individual patient may experience as they progress from referral and diagnosis through to treatment.
Percutaneous Transhepatic Cholangiogram (PTC)	Percutaneous transhepatic cholangiography (PTC) is a procedure performed for diagnostic and/or therapeutic purposes by first accessing the biliary tree with a needle and then usually shortly after that with a catheter (percutaneous biliary drainage or PBD). At some point during the procedure, contrast is injected into one or more bile ducts (cholangiography) and also possibly into the duodenum. PTC may be performed with fluoroscopic guidance only or also with ultrasound (US) guidance.
PET (positron emission tomography) scan	Also called PET imaging or a PET scan. It is a diagnostic examination that involves the acquisition of physiologic images based on the detection of positrons. Positrons are tiny particles emitted from a radioactive substance administered to the patient. The subsequent views of the human body developed by this technique are used to evaluate a variety of diseases.
Positive margin	Positive margin refers to cancer in which the surgeon is physically unable to remove all of the disease with a surrounding rim or margin of healthy normal tissue, and so there is concern that it is possible that cancerous disease might remain/have been left behind.
Radiotherapy	A treatment for cancer that uses high energy ionising radiation (usually X-rays) to kill cells.
Red Flag Referral	A term used across the Northern Ireland Health Service to speed up appointments when a GP feels there is a possibility that a patient's

	symptoms could indicate cancer. This ensures they will see a specialist as quickly as possible.
Resection margins	These are the areas around a block of tissue that have been cut (resected) during surgery to remove a tumour from the body. To ensure all the tumour has been removed, surgeons aim to have a rim of healthy normal tissue at all the margins – these are called 'clear' or 'negative margins'. If tumour cells are found at any of the margins these are called 'involved' or 'positive' margins and implies that not all the tumour has been removed. Resection margins are usually assessed by pathologists and are an important factor when considering the treatment options for a patient.
Residual tumour (R)	The presence or absence of any residual tumour in the body following surgical removal of the main tumour can be assessed and coded by pathologists using the letter 'R'. If the resection margins are negative or clear, this is called an R0 resection, and it implies that all the main tumour was removed at surgery. However, if the margins are positive then this indicates that there is residual tumour remaining in the body. These are called either R1 resections (if tumour cells can only be seen with a microscope) or R2 resections (when the tumour is visible to the naked eye).
Stage	A way of describing the size of a cancer and the extent to which it has grown or spread from its original site. Staging is important because it helps decide which treatments are required. Staging involves clinical, surgical and pathology assessments.
Systemic therapy	Systemic therapy refers to any type of cancer treatment that targets the entire body. For example, chemotherapy, hormone therapy, immunotherapy.
Total Pancreatectomy	This is very major surgery and involves removal of the whole part of the pancreas, duodenum, part of the stomach, gallbladder, part of the bile duct spleen and the surrounding lymph nodes.
Trust	An organisation within the HSC, made up of one or more hospitals, and generally serving one geographical area.
Ultrasound scan	A type of imaging technique, which uses high-frequency sound waves to generate images of the body's organs.
Whipple's Resection (Pancreaticoduodenectomy)	In this operation the head of the pancreas, duodenum, pyloric antrum of stomach, gallbladder and a portion of the common bile duct are removed. Following surgery the remainder of the pancreas, bile duct and stomach are re-joined to the intestine.

Abbreviations

Term	*Meaning*
A&E	Accident & Emergency
ASNS	Age-Standardised Net Survival
BCH	Belfast City Hospital
BHST	Belfast Heath & Social Care Trust
BSC	Best Supportive Care
CaPPs	Cancer Patient Pathway System
CIO	Cancer Intelligence Officer
CNS	Clinical Nurse Specialist
COPD	Chronic Obstructive Pulmonary Disorder
CT	Computerised Tomography
DCO	Death Certificate Only registration
DOH	Department of Health
DVT	Deep Vein Thrombosis
ERCP	Endoscopic Retrograde Cholangiopancreatography
EUS	Endoscopic Ultrasound
GLOBOCAN	Global Cancer Observatory
GP	General Practitioner
HPB	Hepato-Pancreato-Biliary
HSC	Health & Social Care
ICD O-3	International Classification of Diseases for Oncology 3rd edition
MDT	Multi-disciplinary Team
MIH	Mater Infirmorum Hospital Belfast
MRCP	Magnetic Resonance Cholangiopancreatography
MRI	Magnetic Resonance Imaging
NET	Neuroendocrine Tumours
NHS	National Health Service
NI	Northern Ireland
NICE	National Institute of Health and Clinical Excellence
NICR	Northern Ireland Cancer Registry
NIPACS	Northern Ireland Picture Archive and Communications System
NIPanc	Northern Ireland Pancreatic Cancer Charity
NOS	Not Otherwise Specified
PAS	Patient Administration System
PCT	Palliative Care Team
PDG-PET/CT	Fluorodeoxyglucose Positron Emission-CT-scanning
PERT	Pancreatic Enzyme Replacement Therapy
PET-CT	Positron Emission Tomography
PHA	Public Health Agency
pNET	Pancreatic Neuroendocrine Tumour
PTC	Percutaneous Transhepatic Cholangiogram
QPI	Quality Performance Indicators
QUB	Queen's University Belfast
RISOH	Regional Information System for Oncology and Haematology
RVH	Royal Victoria Hospital Belfast
SMA	Superior Mesenteric Artery
SMV	Superior Mesenteric Vein

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