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on Pancreatic Cancer

April 2021

All-Party Parliamentary Group on Pancreatic Cancer Report

The Impact of Covid-19 on Pancreatic Cancer Treatment and Care in England

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CONTENTS

FOREWORD BY JIM SHANNON MP

CHAIR OF THE ALL-PARTY PARLIAMENTARY GROUP ON PANCREATIC CANCER

The COVID-19 pandemic has had an unprecedented impact on the world and the NHS. But for many people with pancreatic cancer, the impact has been nothing short of devastating. Dealing with a diagnosis of the deadliest common cancer is difficult enough in normal times, but the past year has added significant new challenges for many. In the best cases, disruption has been minimised, and the main change people have had to endure has been an increased number of virtual appointments – but for the majority, the impact has been far worse. Indeed, in the worst cases, delays to treatment and surgery have meant that people have missed their treatment window, and with it, the chance of survival – leaving them with only end-of-life care options.

The All-Party Parliamentary Group on Pancreatic Cancer has gathered intelligence on the impact of the pandemic on pancreatic cancer services from across the country, through speaking to expert clinicians, researchers, people with pancreatic cancer and their families. At the start of 2020 we already faced a situation in which the UK trails behind other countries in survival statistics, ranking 28th out of 36 countries with comparable data.[1] Unfortunately, the pandemic threatens to make an already unacceptable situation worse, setting back hard-earned progress in tackling the disease.

This report shows what that impact looks like: from the low-level system problems that have failed people with pancreatic cancer, to the shocking overarching prediction that the pandemic's impact on treatment would lead to 521 excess pancreatic cancer deaths by March 2021. It illustrates a clear need for rapid investment in, and resourcing of, pancreatic cancer services to ensure that we now do all we can to rebuild. For many people with pancreatic cancer, it is sadly now too late to help, but we hope that this report acts as a catalyst for more focus on this deadly disease in the future and paves the way for improvements to support, treatment and care for those with the deadliest common cancer.

Jim Shannon

Jim Shannon MP

Chair of the All-Party Parliamentary Group on Pancreatic Cancer

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[1] CONCORD-3: 5-year survival data for the period 2010-2014. All common cancers, represents the cancers available in CONCORD-3 which collectively represent 75% of all cancers diagnosed worldwide.

INTRODUCTION

Pancreatic cancer is the deadliest common cancer. One in four people die within a month of diagnosis, and three in four people die within a year. Less than one in 10 people will survive five years. These statistics are incredibly poor, and unparalleled amongst most common cancers. Yet the COVID-19 pandemic may further worsen these outcomes. The combined impact of clinical prioritisation, individual patient infection risk, and the NHS' continued focus on COVID-19 may continue to negatively impact treatment and care for people with pancreatic cancer for some time to come.

The COVID-19 pandemic has had an unprecedented impact on the NHS and its ability to deliver urgent and critical care. In early 2020, increasing numbers of critically unwell patients with COVID-19 entered hospital, reducing availability of high dependency units and intensive care units, and leading to reduced surgical capacity. In response, the NHS reorganised acute and elective care pathways and systems to deal with the influx of COVID-19 patients into intensive care and try to maintain treatment capacity for non-COVID-related health needs.

Despite the NHS's system reorganisation, treatment and care provision for all cancers has continued to face unparalleled challenges during the COVID-19 pandemic. Optimal management for cancer care requires people with cancer to have access to multi-disciplinary services – such as nurses, dietitians and intensive care. However, the availability of cancer professionals has been reduced through COVID-19 infection, self-isolation and re-deployment to other areas. Cancer patients also require multiple and frequent attendances to hospital for diagnosis, treatment and supportive care – but the increased risk to exposure to COVID-19 has meant these attendances have had to be minimised.

COVID-19 has also posed a higher risk for people with all types of cancers. Cancer diagnosis, and its corresponding treatments, both increase the severity and mortality of COVID-19 infection.[2] Therefore, the added COVID-19 risk associated with treatment has meant that in some cases, the risk of treatment has outweighed the benefits – particularly for older patients and patients with significant comorbidities.

The NHS has undertaken re-organisation and prioritisation of services to focus on maintaining emergency surgery and treatment. NHS England (NHSE) and NICE published guidance on the clinical management for non-coronavirus patients requiring acute treatment,[3] with cancer

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[2] https://www.nice.org.uk/Media/Default/About/COVID-19/Specialty-guides/cancer-and-COVID-19.pdf

[3] https://www.nice.org.uk/Media/Default/About/COVID-19/Specialty-guides/cancer-and-COVID-19.pdf

surgery prioritised 1 – 3 based on emergency care for life threatening conditions and systemic anti-cancer therapy prioritised 1 – 6, based on the curative intent and risk-benefit associated with treatment.[4] Pancreatic cancer surgery was prioritised in level 2: ‘elective surgery with expectation of cure’ and ‘needed within 4 weeks to save life/progression beyond operability’. This guidance also laid out chemotherapy prioritisation criteria, ranking priority by likelihood of survival. As a result, it placed people with inoperable pancreatic cancer in the lowest two priority groups: ‘Non-curative therapy with a high (>50%) chance of palliation/temporary tumour control but <1 year life extension’, and ‘Non-curative therapy with an intermediate (15–50%) chance of palliation or temporary tumour control and <1 year life extension.’[5] This will have meant that for many, their pancreatic cancer was not treated as a priority, and they were not able to access treatment that might have improved their quality of life in their final months or given them precious extra time.

Pancreatic cancer is an aggressive and rapidly progressing cancer. Delays in treatment can rapidly lead to patients becoming inoperable: surgical delays for three or six months can have up to 17% or 36% reduction in survival, for stage 2 and stage 3 pancreatic cancer.[6] Pancreatic cancer patients treated in the advanced and metastatic stage have few treatment options and limited survival and any delays or disruption to the best standard of care can shorten their length of life.

Pancreatic cancer currently has the lowest survival rate of all common cancers, with 7% five-year survival, and unwarranted variation in treatment and care further worsening outcomes for many. The full extent of the impact of the COVID-19 pandemic on pancreatic cancer outcomes is yet to be realised, but may include delayed and missed diagnosis, revised clinical pathways, and dose modification all resulting in faster disease progression, more patients receiving no treatment and ultimately worse outcomes. It is important to understand and evaluate the impact of the pandemic on pancreatic cancer treatment, care and outcomes as well as identify innovations and best practice that have helped to reduce the impact, in order to inform health service planning for future waves of COVID-19 or future pandemics.

In this context, the APPG on Pancreatic Cancer has sought to capture the impact of the pandemic on people with pancreatic cancer. Through its charity partners, this has included surveying people affected and their families and carers, collating patient accounts from charity members’ public-facing support services, and speaking to health professionals working in

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[4] https://www.nature.com/articles/s41416-020-0980-x

[5] https://www.nice.org.uk/Media/Default/About/COVID-19/Specialty-guides/cancer-and-COVID-19.pdf

[6] https://www.medrxiv.org/content/10.1101/2020.04.21.20073833v1.full.pdf

pancreatic cancer across the country to understand their experience of the pandemic. This report aims to highlight the impact of the pandemic: specifically, the impact on diagnosis, treatment and supportive care. It also aims to analyse and evaluate the responses that NHS bodies have taken to maintain pancreatic cancer services. It identifies ongoing issues and concerns, and also highlights areas of excellent practice and innovation during the pandemic, in the hope of making the best of this international disaster and ensuring lessons are learned going forward.

DIAGNOSIS

At the height of the first peak of the pandemic, urgent referrals for cancer were down by 75%, equating to an estimated 2,300 missed cancer diagnoses every week.[7] As a result of public concern about COVID-19, fears about burdening the NHS and reluctance from GPs to refer,[8] fewer people saw a specialist for suspected upper GI cancer. Due to the vague and non-specific nature of symptoms for pancreatic cancer, many people may have been reluctant to present to primary care; with symptoms seen as less important in the context of COVID-19. Urgent referrals for upper GI cancer were down to only 5,623 in April compared with 15,000 a month prior to the pandemic. [9] Over the period March 2020 to August 2020, there were 26% fewer urgent upper GI referrals compared to the same period in 2019, resulting in 25,666 less referrals for upper GI cancer.[10] Assuming the normal 4.2% conversion rate for upper GI referrals[11], over 1000 upper GI cancers were potentially not diagnosed during this period.

The COVID-19 pandemic significantly reduced the NHS' capacity to provide diagnostic and staging investigations for pancreatic cancer, with less than a quarter of UK pancreatic cancer specialist centres having normal availability of diagnostic pathways.[12] The British Society of Gastroenterology advised that gastroenterology endoscopic services were only to be used in essential procedures, as it is an aerosol-generating procedure with high COVID-19 transmission.[13] Endoscopy was only advised to continue for emergencies, while two-week wait referral cancer staging endoscopic ultrasounds were advised to be discussed on a case-by-case basis.[14]

As a result, endoscopic services were significantly reduced at several points since the pandemic began. Over the first six weeks, only 14% - 22% of pancreatic cancer centres had normal availability of endoscopic ultrasound (used to assess operability) and 4% - 21% had

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[7] https://scienceblog.cancerresearchuk.org/2020/04/21/how-coronavirus-is-impacting-cancer-services-in-the-uk/

[8] https://www.england.nhs.uk/midlands/2020/05/01/nhs-urges-people-to-get-cancer-symptoms-checked-as-gp-referrals-drop-by-73/#:~:text=Latest%20figures%20have%20

[9] Upper GI two-week wait referrals were 14,517 in March 2020 and 16,215 in February 2020.

[10] https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/monthly-prov-cwt/

[11] http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/tww_conversion_and_detection

[12] Impact of SARS-CoV-2 Pandemic on Pancreatic Cancer Services and Treatment Pathways: United Kingdom Experience, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (*Unpublished manuscript)*

[13] BSG. GI Endoscopy Activity and COVID-19: Next steps 2020 2020.

[14] https://www.bsg.org.uk/covid-19-advice/endoscopy-activity-and-covid-19-bsg-and-jag-guidance/

normal availability of staging laparoscopy.[15] Capacity for endoscopic services continued to be reduced even in July, with 22% of centres still having limited ability to undertake these.[16] [17] National data from NHSE also shows that endoscopic procedures remained significantly impacted in December 2020, with longer median waiting times and a higher proportion of patients waiting longer than six weeks compared to December 2019. [18]

Pancreatic cancer centres' capacity for cross-sectional imaging was less impacted than invasive services: after initial disruption, availability across pancreatic cancer centres returned to normal within 13 weeks,[19] and national imaging activity in December 2020 was the same as December 2019 activity.[20] However, a survey of UK pancreatic units by the Association of Upper GI Surgeons in February 2021 highlighted fears of continuing disruption, showing that nearly a third of hospitals (32%) had lower than normal availability of staging laparoscopy during February 2021. This availability is, however, significantly higher than during the first wave of the pandemic, when 88% of hospitals had lower than normal capacity.[21]

The combination of reduced public presentation to primary care with concerning symptoms and reduced urgent cancer referrals, coupled with reduced diagnostic capacity, will have led to both delayed and missed pancreatic cancer diagnoses as well as delayed treatment initiation during the first months of the pandemic. This will in turn have led to later stage presentation, and missed opportunities for treatment. This is especially concerning given the poor prognosis in late-stage metastatic pancreatic cancer, where one-year survival is only 8%.[22]

This missed and delayed cohort of cancer patients will continue to present in coming months, alongside the cases that would normally present during this time - adding to diagnostic and treatment demand and pressure. NHS data shows that urgent upper GI referrals were up 4%

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[15] Impact of SARS-CoV-2 Pandemic on Pancreatic Cancer Services and Treatment Pathways: United Kingdom Experience, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (*Unpublished manuscript)*

[16] The ability to undertake PTC or ERCP returned to normal by week 11 or 18 respectively

[17] Impact of SARS-CoV-2 Pandemic on Pancreatic Cancer Services and Treatment Pathways: United Kingdom Experience, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (*Unpublished manuscript)*

[18] https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2021/02/DWTA-Report-December-2020.pdf

[19] Impact of SARS-CoV-2 Pandemic on Pancreatic Cancer Services and Treatment Pathways: United Kingdom Experience, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (*Unpublished manuscript)*

[20] https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2021/02/DWTA-Report-December-2020.pdf

[21] Pancreatic Cancer Services and Treatment During the COVID-19 Pandemic: A National Review, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (*Unpublished manuscript)*

[22] https://www.pancreaticcancer.org.uk/wp-content/uploads/2020/09/new-insights-on-pancreatic-cancer.pdf

over the period September to December 2020 compared to the same period in 2019. Upper GI referrals were up 11% in September compared to 2019 levels but the proportion seen within 14 days was down almost 10%, suggesting that patients who were missed during the spring are now presenting to primary care, adding further pressure on NHS diagnostic capacity.

TREATMENT

The first wave of the COVID-19 pandemic had a twofold impact on pancreatic cancer treatment. Firstly, there was a reduced capacity to deliver systemic and surgical treatment for all pancreatic cancer treatment modalities during the first 6 weeks of the pandemic (16th March – 26th April).[23] Secondly, the added COVID-19 risk associated with treatment may have shifted the harm-benefit balance of treatment, particularly for elderly people and people with comorbidities. This continued in the second wave, in some places to an even worse extent.

An excess mortality model predicted that, with 40% of the pancreatic cancer population affected, the COVID-19 pandemic's impact on treatment would lead to 521 excess pancreatic cancer deaths by March 2021, with a range of 208 – 1042 dependant on the relative impact of the emergency (RAE).[24] [25] This is compared to 6,270 modelled excess deaths from all incident cancer cases. Despite being only the twelfth most common cancer, this places pancreatic cancer as the fifth largest incident cancer death due to COVID-19. The four more affected cancers include lung cancer and bowel cancers - diseases with far higher incidence.

SURGERY

Surgery is the only potentially curative treatment for people with pancreatic cancer. However, the immediate impact of the pandemic led to reorganisation and prioritisation of theatre space and intensive care units, limiting upfront resection capacity in the initial phase of the pandemic. Provision for pancreatic cancer surgery was reduced to 20% of normal capacity during the first six weeks of the pandemic, with 17% - 25% of units having no capacity for pancreatic cancer surgery and median pancreatic operations were reduced by 40% compared to 2019.[26] Where surgical capacity or resource was limited, neo-adjuvant chemotherapy or chemoradiotherapy,

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[23] Impact of SARS-CoV-2 Pandemic on Pancreatic Cancer Services and Treatment Pathways: United Kingdom Experience, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (*Unpublished manuscript)*

[24] https://www.medrxiv.org/content/10.1101/2020.05.27.20083287v1

[25] This model assumes the adverse health consequences of the COVID-19 emergency, based on the summative impact of ill-health in those infected with COVID-19, net adverse health due to changes in health services, net adverse health consequences of physical distancing and adverse health consequences of economic downturn.

[26] Impact of SARS-CoV-2 Pandemic on Pancreatic Cancer Services and Treatment Pathways: United Kingdom Experience, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (*Unpublished manuscript)*

including hypofractionated RT/CRT could have been considered, with one third of centres moving from surgery-first to neoadjuvant chemotherapy.[27]

In the context of limited healthcare resource, NHS England prioritised cancer surgery 1 – 3 based on emergency need for life threatening conditions, with pancreatic cancer surgery within level 2: *elective surgery with expectation of cure* and *needed within 4 weeks to save life/progression beyond operability.*[28] Over the course of the pandemic, NHS England and devolved nations have worked to restore surgical capacity with the set-up of 'COVID-19 free' ring-fenced surgery hubs and use of the independent sector, however, after the first wave even by July 2020 only half of centres had restored normal capacity for pancreatic cancer surgery. [29]

Adjuvant chemotherapy is the gold standard of care for operable pancreatic cancer, significantly improving five-year survival for pancreatic cancer patients.[30] The first wave of the pandemic also had a significant impact on the delivery of adjuvant chemotherapy, with less than half of centres having normal capacity in the first ten weeks of the pandemic.[31] Decisions to give adjuvant chemotherapy were also based on risk-benefit balance, and weighing the effectiveness of combination chemotherapy against increased risk, with treatment able to be deferred for up to 12 weeks post-surgery.[32]

This disruption continued during the second wave, with three quarters of hospitals offering less than normal surgery capacity in February 2021, and 40% fewer operations being performed nationally compared to before the pandemic.[33] Further, 25% of patients were reported to be undergoing non-curative ('bypass') operations compared to only 7% before the pandemic, suggesting that a greater proportion of operations are happening too late due to delays caused by the pandemic.

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[27] Impact of SARS-CoV-2 Pandemic on Pancreatic Cancer Services and Treatment Pathways: United Kingdom Experience, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (*Unpublished manuscript)*

[28] https://www.nice.org.uk/Media/Default/About/COVID-19/Specialty-guides/cancer-and-COVID-19.pdf

[29] Impact of SARS-CoV-2 Pandemic on Pancreatic Cancer Services and Treatment Pathways: United Kingdom Experience, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (*Unpublished manuscript)*

[30] https://www.nature.com/articles/s41416-020-0980-x

[31] Impact of SARS-CoV-2 Pandemic on Pancreatic Cancer Services and Treatment Pathways: United Kingdom Experience, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (*Unpublished manuscript*

[32] https://www.nature.com/articles/s41416-020-0980-x

[33] Pancreatic Cancer Services and Treatment During the COVID-19 Pandemic: A National Review, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust *(Unpublished manuscript)*

Pancreatic cancer is an aggressive and rapidly progressing cancer, where delays in surgery can rapidly lead to patients becoming unresectable. Surgical delays of three months can have up to an 17% reduction in survival and a surgical delay of six months would lead to a 20% - 36% reduction in survival, for stage two and three cancer. [34] These delays to surgery were modelled to lead to 80 and 138 attributable deaths in one-year for three month and six-month delay.

SYSTEMIC ANTI-CANCER THERAPY (SACT)

Systemic anti-cancer therapy (SACT) for late-stage patients was restricted due to reduced capacity to deliver treatment and the increased COVID-19 risk to patients undergoing chemotherapy shifting the balance of risk-benefit. NHS England guidance also prioritised SACT as lower priority in advanced (4 – 5) and metastatic (4 – 6) pancreatic cancer as compared with operable pancreatic cancer (2 – 4), due to the poor prognosis of pancreatic cancer and limited survival benefit of systemic treatment in late-stage disease.[35]

For metastatic disease, FOLFIRINOX or gemcitabine combination or monotherapy are recommended in the NICE guidelines, however, the clinical consensus was that the risk of COVID-19 may outweigh the benefit of treatment, given the low median survival with chemotherapy, with decisions to give palliative chemotherapy recommended to be highly selective and limited in duration. [36]

In addition to the increased COVID-19 individual risk associated with treatment and increased stringency of treatment selection, there was also a reduction in capacity to deliver palliative therapy, to 30% of normal capacity during weeks five to six (13th – 26th April) of the pandemic and 42% of centres had less than 50% capacity to deliver palliative therapies.[37]

Overall, multiple factors have impacted the provision of pancreatic cancer treatment during the pandemic. Increased COVID-19 risk has been associated with increasing stringency of treatment selection and dose modification, coupled with reduced capacity to deliver palliative therapies and lower national prioritisation. As a result, 30% of pancreatic cancer clinicians reported that palliative patients were either not receiving therapy or were receiving simplified

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[34] https://www.medrxiv.org/content/10.1101/2020.04.21.20073833v1.full.pdf

[35] https://www.nice.org.uk/guidance/ng161/chapter/3-Systemic-anticancer-treatments

[36] https://www.nature.com/articles/s41416-020-0980-x

[37] Impact of SARS-CoV-2 Pandemic on Pancreatic Cancer Services and Treatment Pathways: United Kingdom Experience, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (*Unpublished manuscript*

versions of treatment[38] and 60% of pancreatic cancer clinicians estimate that 60% or less of their palliative patients have received the therapy they would have usually received during the first wave.[39]

Given that people who are treated in the advanced and metastatic setting have limited treatment options and limited survival already, any delays, cancellations or dose modifications to treatment can be devastating for the survival, mental wellbeing, and overall quality of life of these people.

CLINICAL TRIALS

Clinical trials have also been adversely affected by the pandemic. Trials have struggled to recruit throughout the pandemic, whilst issues with recruitment to the COVID-19 trials has undermined efforts to restart level two and three trials, within which most pancreatic cancer trials fall. For people with pancreatic cancer, access to clinical trials is crucial: with this cancer being so deadly, and late diagnoses being all too common, often the new treatments being offered by clinical trials might be people's only option for life-extending treatments. We have also heard of issues with restarting multi-site clinical trials, due to the impact of COVID-19 varying greatly across the UK. This is a huge concern, especially in smaller patient groups that require a UK-wide patient pool to effectively power trials – a prime example of this being Precision-Panc, a research programme led by Glasgow University focusing on uncovering the molecular profile of people with pancreatic cancer and matching this to the most effective clinical trials for them. Not having access to this kind of innovative treatment will inevitably mean that many people with pancreatic cancer have no choice of treatment at all.

As a country, we remain significantly behind other nations in restarting clinical research activity and this is already impacting on patients. Only 12% of non-commercial studies were open to recruitment in mid-April 2020, with 72% either paused, stopped or cancelled completely due to the pandemic. Restart of clinical trials has since recovered slightly as of the end of 2020, but nowhere near fully.

TREATMENT SELECTION FOR ELDERLY PATIENTS

COVID-19 has increased the risks associated with treatment and shifted the harm-benefit ratio of treatment, particularly for older patients with significant comorbidities leading to some

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[38] Although many clinicians reported that palliative patients received the same therapeutic regime (59%, n = 10/17).

[39] A further 29% estimate that 60-80% have received the normal therapy.

patients having reduced (‘milder’) treatment regimes. While strategies for pancreatic cancer treatment should balance the impact of the increased COVID-19 risk and benefit of treatment, reduced (‘milder’) regimes will impact the efficacy and outcomes for patients, with a disproportionate impact on elderly patients and patients with significant co-morbidity.

At the start of the pandemic, the clinical consensus within the pancreatic cancer community was that the increasing risk of mortality with COVID-19 may outweigh the benefit of an intervention for elderly and co-morbid patients. The potential additional risk associated with surgery was also considered, with 96% of pancreatic cancer clinicians believing that the post-operative consequence of acquiring COVID-19 would be greater risk of death. At the start of the pandemic, clinical vignettes show that elderly patients were less likely to be offered curative treatment, with only 44% of pancreatic centres offering this. Equally, 91% of centres said they would not offer treatment to 82-year-olds with COPD. The added risk of COVID-19 for chemotherapy may have also led to more ‘mild’ regimes being given to older people with pancreatic cancer, which may have reduced efficacy of treatment and led to faster cancer progression. In the context of limited healthcare resource and the continued increased COVID-19 risk for elderly patients, treatment is likely to remain selective to some extent and may still exclude older patients and patients with co-morbidity.

EXPERIENCES OF PEOPLE WITH PANCREATIC CANCER

PANCREATIC CANCER UK'S PATIENT SURVEY

To assess the impact of the pandemic on pancreatic cancer patients, Pancreatic Cancer UK surveyed 124 pancreatic cancer patients and their families and carers online to understand the impact of COVID-19 on pancreatic cancer treatment and care. The survey was conducted between 16 April – 11 June 2020 and was distributed via Pancreatic Cancer UK social media channels, newsletters and through direct email communication to patients.

Overall, 60% of respondents reported that their treatment or care had been impacted by the COVID-19 pandemic, either through delayed or cancelled treatment, receiving insufficient information or support, their own coronavirus diagnosis or due to social distancing measures. The COVID-19 pandemic also caused concern and worry to patients who had not yet been impacted, with a further 12% worried their treatment or care might be impacted.

For people who had been impacted by the pandemic, the most common reported impact of the pandemic was treatment delay or cancellation for systemic treatment such as chemotherapy (36% of people who had been impacted). This compared to only 7% of people reporting that their surgery had been delayed, which reflects the small proportion of patients who are able to undergo surgery. A further 7% of people reported that they had clinical trials suspended or delayed, due to the COVID-19 pandemic.

In March 2020, guidance was issued advising clinically vulnerable patients, including those with pancreatic cancer, to 'shield'. This reduced people's support networks, with 29% of respondents to the Pancreatic Cancer UK patient survey reporting being unable to receive support or comfort from friends or family members due to social distancing or self-isolation / shielding measures. Many more people with pancreatic cancer were worried about the impact of self-isolation and shielding (42%). As a result of self-isolation and shielding, many people have reported receiving a pancreatic cancer diagnosis alone which is something that should not happen.

All pancreatic cancer patients need access to a dietitian and specialist CNS to receive support with symptoms and psychological and nutritional management. However, a common patient-reported impact of the pandemic was receiving insufficient information on support about treatment, symptom management and palliative care. Prescribing data collected by NHS England suggests that pancreatic enzyme prescriptions dropped 19% at the height of the pandemic in May compared to March, potentially either reflecting the reduced pancreatic cancer patients in the system or reduced nutritional support and management of patients. [40][41]

PANCREATIC CANCER UK SUPPORT LINE INTELLIGENCE

Pancreatic Cancer UK's Support Line provides advice and support to people living with pancreatic cancer through their Support Line, which is staffed by specialist pancreatic cancer nurses. During the pandemic, this emotional support has been needed by patients more than ever. In the first wave, calls to the Support Line were up by 58% on the normal weekly average, and there was a 34% increase in the number of people being supported each week.

The Support Line has also been contacted by a larger proportion of palliative patients than normal over the last year, reflecting an information gap for this group. Pancreatic Cancer UK has received reports of people receiving no support between diagnosis and death. This was also reported by more than a quarter of respondents to Pancreatic Cancer UK's patient survey.

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[40] https://openprescribing.net/bnf/010904/ - BNF code Pancreatin

[41] Note that this is only a proxy indicator as Pancreatic Enzymes are also prescribed to people with cystic fibrosis.

BEST PRACTICE AND INNOVATION

On the 30th November 2020, NHS England oulined a commitment to make available additional funding, including £4 million to lock-in innovation developed during the pandemic. A number of innovations and best practice examples were developed as a result, allowing pancreatic cancer treatment, care and support to be better delivered during the pandemic.

EXAMPLES OF EXCELLENCE

PENINSULA RAPID DIAGNOSTIC CENTRE PANCREATIC CANCER PATHWAY

Alongside the roll out of the new non-cancer site-specific diagnosis pathway Peninsula have reviewed the pancreatic pathway as part of the rapid diagnosis programme, strengthening the links between the new non-site-specific pathway and the Hepato-Pancreato-Biliary (HPB) services. They have ensured they have diagnostic services available to patients with rapid-onset jaundice within 48 hours, so that patients have a better chance of receiving surgery. The non-site-specific pathway is supported by a care navigator, to guide patients through the pathway and act as a point of contact. Patients in the non-site-specific pathway and rapid diagnosis pancreatic cancer pathway participate in a patient experience ‘pulse’ survey, followed by SMART improvement cycles.

GREATER MANCHESTER CANCER HUB

Greater Manchester developed the GM Cancer Hub, providing an oversight and coordination function to deliver a system-wide single queue for diagnostics and treatment of patients referred into secondary care. This approach has allowed patients to have equitable access to diagnostics and treatment, and ensure system-wide matching of capacity and demand. In Greater Manchester, patients referred via HPB cancer referral have been triaged and seen via video/teleconference in Manchester, before being given diagnostic tests with infection control and risk management and referred to the specialist MDT. Greater Manchester worked with trusts to ensure and implement safety netting to monitor patients referred into secondary care.

Also in Manchester, the HPB Pathway Board developed a protocol for the management of suspected HPB cancer referrals throughout the pandemic. Systemic Anti-Cancer Therapy (SACT) guidelines, radiotherapy prioritisation guidelines, and risk stratification documents were produced to allow for equitable management of treatment prioritisation where necessary.

LIVERPOOL CANCER ALLIANCE

The HPB team in Liverpool undertook excellent work to ensure the impact on pancreatic cancer treatment pathways was minimised during the pandemic. The median waiting time in 2020 was 13 days from clinic to surgery compared to 10 days in 2019, with only a marginal increase due to the need to self-isolate before surgery. 64 operations were undertaken between 1st March and 31st July 2020, compared to 74 in same period in 2019. As a result of the measures taken, there was no waiting list for surgery in Liverpool, and waiting times remained similar to 2019. Further, the number of chemotherapy and radiotherapy treatments in March to July 2020 was higher than the same period in 2019. The peer support group (The "Buddy" group) has continued to work over the telephone, supporting patients newly diagnosed with pancreatic cancer.

SUPPORTIVE CARE

A number of Cancer Alliances identified a range of proactive and innovative practices to try to continue to provide holistic care. The utilisation of technology often enabled patients to stay informed and involved in decision-making regarding their treatment, with clinics continuing via telephone. In Cheshire and Merseyside, the peer support group (The "Buddy" group) continued to work over the telephone, supporting patients newly diagnosed with pancreatic cancer. In Greater Manchester, every patient had access to the specialist nurse and dietetic input and telephone and video consultations were utilised to allow more contact with patients.

Cancer Alliances often reported that they had ensured patients had information and were informed and involved in discussion about risks and benefits of treatment during COVID-19, and that they were given clear communication when their care was disrupted. Peninsula introduced the 'My Sunrise' app to improve the holistic support for patients and Cancer Matters Wessex's website provides information and individual Trust-specific vignette videos for patients. Other Cancer Alliances highlighted COVID-19 helplines for patients, appointed a CNS with a remit for pancreatic cancer, and produced an information leaflet for patients who were preparing and shielding for surgery.

Access to palliative and end-of-life care was highlighted as even more vital, with additional support required due to the anxiety around the pandemic. Many Cancer Alliances reported that clinicians have continued to provide personalised care planning matched to patients' needs throughout the pandemic. They have worked hard to ensure that people's care is appropriately tailored to their needs. Some Cancer Alliances reported that they have continued to include patients in choices about their palliative and end-of-life care, including advance care planning frameworks (e.g. Deciding Right and Caring for the Dying Patient care plan).

CONCLUSION

In line with increasing cases, hospitalisations and deaths, the UK entered a second COVID-19 wave and a subsequently a second lockdown on the 5th November 2020. On the 30th November, NHS England committed to ensuring the recovery of cancer services through the second wave. However, despite measures taken, we have once again seen pancreatic cancer treatments cancelled up and down the country.

The long-term impact of reduced public presentation to primary care and reduced urgent referrals at the height of the pandemic has not yet been fully realised. The missed and delayed cohort of cancer patients not yet in the system will have to come through in the subsequent months alongside incident cancer cases, adding to diagnostic and treatment demand. These people will naturally be presenting at a later stage and so are more likely to be, or become, inoperable, due to diagnostic delays and reduced investigative capacity. The impact of revised treatment pathways during the first wave has also yet to be realised, with people who were bridged on neo-adjuvant chemotherapy and who need surgery potentially increasing pressure on services further down the line.

As highlighted, due to risk stratification, elderly and comorbid patients are less likely to be offered treatment, in the context of limited healthcare resource and the continued increased COVID-19 risk for elderly patients. Treatment is likely to remain selective for some time, and may still exclude older patients and patients with co-morbidity.

The holistic impact on patients may also continue to be felt, with some people feeling isolated, receiving their diagnosis and treatment alone and less able to receive support from family and friends. All of this is likely to have an enormous emotional impact on people, reduce their quality of life, their experience of care and ultimately, their chance of survival.

The combined impact of reduced cancer referrals, reduced capacity for treatment, revised treatment pathways and added COVID-19 risk on the one-year survival for pancreatic cancer is also yet to be seen.[42] Aforementioned modelling data showing that the COVID-19 pandemic would lead to 521 excess pancreatic cancer deaths by March 2021 has the alarming potential to be the tip of the iceberg, but even if those data are accurate, this places pancreatic cancer as the fifth largest incident cancer death due to COVID-19.[43] [44]

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[42] https://www.medrxiv.org/content/10.1101/2020.05.27.20083287v1

[43] https://www.medrxiv.org/content/10.1101/2020.05.27.20083287v1

[44] This model assumes the adverse health consequences of the COVID-19 emergency, based on the summative impact of ill-health in those infected with COVID-19, net adverse health due to changes in health services, net adverse health consequences of physical distancing and adverse health consequences of economic downturn.

RECOMMENDATIONS

In the presence of the COVID-19 vaccine, and as we begin to tentatively look to a future outside of the pandemic, it is essential that pancreatic cancer patients do not continue to impacted by long-term lingering effects of the COVID-19 pandemic. It is also crucial that innovations and new ways of working created during the pandemic continue and learning is enshrined for future waves and pandemics.

To this end, the APPG are calling for a number of key actions to ensure pancreatic cancer services both recover from the pandemic and further improve:

1. ACCESS TO DIAGNOSIS, SURGERY AND TREATMENT IS FULLY RESTORED AS PROMPTLY AS POSSIBLE

Many people with pancreatic cancer have had their surgery or other treatment delayed or cancelled during the COVID-19 crisis, and this led to a backlog in treatment and surgery. Cancer Alliances and Health Boards across the UK must work with specialist centres to ensure that people who need surgery or other urgent treatment can access this quickly, and that delays do not continue to drive down people's chances of survival. **The Government should work with NHS England to ensure all Cancer Alliances have systems in place to rapidly increase access to diagnosis, surgery and other pancreatic cancer treatments in order to work through the backlog and deal with future local surges in coronavirus.**

2. CLINICAL TRIALS ARE RAPIDLY RESTARTED FOR PEOPLE WITH PANCREATIC CANCER

For people with pancreatic cancer, clinical trials can be a lifeline. They provide access to new treatments, sometimes for patients who have no other treatment options. But as a country, we remain significantly behind other nations in restarting clinical research activity and this is already impacting on patients. **The Government must work with the NHS to prioritise recruiting to and restarting these trials, ensuring that people with pancreatic cancer across the UK have access to trials and their treatments wherever possible.**

3. PEOPLE WITH PANCREATIC CANCER ARE PROVIDED WITH CONTINUOUS, HOLISTIC CARE AND SUPPORT

There must be a focus on coordinating patient care so that, where COVID-19 surges happen in the future, pancreatic cancer patients don't fall through the cracks. We can learn from Scotland's **cancer navigator roles** in this, ensuring people with pancreatic cancer have continuous and thorough support throughout their journey and in spite of any potential disruption. This will be especially important for local areas dealing with COVID-19 surges in their communities over the next few years, and when planning for any future pandemics. Where people cannot get emotional and practical support from the NHS or other services, clinicians must ensure they are signposted to other forms of support, such as Pancreatic Cancer UK's Support Line and Pancreatic Cancer Action's information pages. **The Government must work with NHS England to put the appropriate systems in place so that all patients, throughout their treatment journey, are provided with holistic support and up-to-date information on support services relevant to them.**

4. UP-TO-DATE DATA IS COLLECTED AND PUBLISHED BY CANCER TYPE, TO AID IN DECISION-MAKING AND STRATEGIC RESOURCING OF SERVICES

System directors must share data that is disaggregated by cancer type across systems both locally and nationally. This will help services to react with agility to problems as they occur. For example, data showing fewer referrals, diagnoses or surgeries for specific cancers can help commissioners and directors to react agilely, and focus on rebalancing services in favour of the worst affected cancers. Pancreatic cancer patients cannot afford to be held up in their treatment journey, and data disaggregation will reveal any blockages in the system and help to resolve them. **The Government must work with NHS England to ensure data is appropriately disaggregated so as to be as helpful as possible in directing an agile and targeted response to the worst-performing cancers.**

With determination and focus, we can achieve these changes and ensure that, in the long-term, pancreatic cancer survival does not become another collateral victim of the COVID-19 pandemic.