

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Effaith yr ôl-groniad o ran amseroedd aros ar bobl yng Nghymru sy'n aros am ddiagnosis neu driniaeth](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on the [impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment](#)

WT 39

Ymateb gan: | Response from: Pancreatic Cancer UK

Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment

Written evidence supplied by Pancreatic Cancer UK

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1. Pancreatic cancer in Wales

1.1 Pancreatic cancer was already a cancer emergency before the Covid-19 pandemic.

1.2 Of the 500 people diagnosed every year with pancreatic cancer in Wales, only 5.7% of people are still alive five years later. One-year survival for pancreatic cancer stands at just 28.4% (2012 – 2016).¹

1.3 A key reason for the poor survival statistics for people with pancreatic cancer in Wales is the commonly critically late diagnosis of the disease. 3 in 5 people are diagnosed at a late stage where potentially curative surgery is not possible.² Their disease has already advanced and surgery to remove part of or all of the pancreas and surrounding organs – the only potential cure for pancreatic cancer – is no longer possible.

1.4 This situation has occurred because of a combination of factors. One key factor is that the symptoms of pancreatic cancer are vague and difficult to pin down. However, this is compounded by patients' experiences of receiving a diagnosis often being uncoordinated and slow, with people commonly attending multiple GP appointments before a referral is made and often bouncing between different pathways. Data for England shows that 44% of people with pancreatic cancer are diagnosed through emergency presentation (e.g. A&E), where one-year survival is only 12.2%.³

¹ CONCORD-3, [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)33326-3/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)33326-3/fulltext)

² <https://phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/>

³ NCRAS, http://www.ncin.org.uk/publications/routes_to_diagnosis

1.5 This data places Wales 34th out of 36 countries with comparable data⁴. This is not a position to be proud of: statistics that have barely changed in the last 45 years, whilst other cancers have seen great improvements largely because of targeted investment, audits and awareness campaigns. Even short delays between diagnosis and having surgery or chemotherapy drastically lower or shorten the chances of survival for people with pancreatic cancer.

1.6 However, due to the impact of COVID 19 on the health service we have seen multiple delays and cancellations to pancreatic cancer diagnosis, treatment and surgery, across the UK. We are concerned there is a real risk that the impacts of the pandemic risk increasing the survival gap between pancreatic cancer and other cancers still further, so that cancer outcomes for pancreatic cancer in Wales fall even further behind similar countries internationally, and the gap between pancreatic cancer survival and survival rates for other cancers also widens.

2. Impact of the pandemic on diagnosis and treatment for people with pancreatic cancer

2.2 The COVID-19 pandemic has had a hugely negative impact on people with pancreatic cancer and threatens to have a lasting impact on the survival chances of people with the disease in the future. The combined impact of delayed diagnoses, altered and cancelled treatments, disrupted research trials, and the NHS' continued focus on COVID-19 may continue to negatively impact outcomes for people with pancreatic cancer for some time to come. This threatens to slow and even halt progress for the considerable future, unless pancreatic cancer services are prioritised and resourced – not just to restore outcomes to pre-pandemic levels, but to take us far beyond these and drive up survival.

2.3 Ultimately, people with pancreatic cancer do not have time to wait.

Diagnosis:

2.4 The impact of COVID-19 is being felt across the entire cancer pathway in Wales.

2.5 Data from England and Scotland indicates that GP referrals for urgent suspected cancer have dropped by over 70%, with Wales expected to show a similar pattern.⁵

2.6 In the wake of the pandemic, where figures from Welsh Government suggested 34,000 fewer people than expected entered the Wales Single Cancer Pathway, rapid and early

⁴ CONCORD-3, Lancet 2018 ([https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)33326-3/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)33326-3/fulltext))

⁵ <https://scienceblog.cancerresearchuk.org/2020/04/21/how-coronavirus-is-impacting-cancer-services-in-the-uk/>

diagnosis is more important than ever before and needs to be a long-term focus if we are to avoid a dip in Welsh cancer survival for the first time in decades.⁶

2.7 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. Additionally, as a result of public concern about COVID-19, fears about burdening the NHS and reluctance from GPs to refer, fewer people saw a specialist for suspected upper GI cancer.

2.8 As diagnoses have likely dropped due to a reduction in cancer referrals, a substantial backlog of undiagnosed cancers is building. These may be picked up at a later stage, albeit when the cancer is less treatable.

2.9 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.⁷ 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.⁸

2.10 It will take some considerable time before diagnostic services are restored to normality. Yet any resource spent on catching up to pre-pandemic levels and working through the backlog acts as a further delay to much-needed focus on improving future outcomes and catching up to other nations' survival rates.

Treatment:

2.11 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.⁹ These delays to surgery were modelled to lead to 80 and 138 attributable deaths in one year for three month and six-month delay (in England).

⁶ <https://stats.wales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Cancer-Waiting-Times/Monthly/suspectedcancerpathwayclosedpathways-by-localhealthboard-tumoursite-agegroup-gender-measure-month>

⁷ 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)

⁸ Pancreatic Cancer Services and Treatment During the COVID-19 Pandemic: A National Review, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (Unpublished manuscript).

⁹ <https://www.medrxiv.org/content/10.1101/2020.04.21.20073833v1.full.pdf>

- 2.12 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 six weeks of the pandemic (16th March – 26th April).¹⁰ 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.
- 2.13 More recently, Welsh Government figures also revealed that almost 60% of cancer patients started their first definitive treatment within 62 days of it first being suspected - below the target of 75%. It means 634 newly diagnosed patients waited longer than they should have done for treatment to start.¹¹
- 2.14 An excess mortality model using data for England 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).^{12 13} 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-19.¹⁴
- 2.15 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 2019.¹⁵ Where surgical capacity or resource was limited, neo-adjuvant chemotherapy or chemoradiotherapy, including hypofractionated RT/CRT could have been considered, with one third of centres moving from surgery-first to neoadjuvant chemotherapy.¹⁶
- 2.16 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.¹⁷ Further, 25% of patients were reported to be undergoing non-curative ('bypass') operations compared

¹⁰ Ibid, Siobhan Chloe McKay.

¹¹ <https://www.walesonline.co.uk/news/health/dire-nhs-wales-figures-show-22558553> December 2021

¹² <https://www.medrxiv.org/content/10.1101/2020.05.27.20083287v1>

¹³ 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

¹⁴ The four more affected cancers include lung cancer and bowel cancers - diseases with far higher incidence.

¹⁵ Pancreatic Cancer Services and Treatment During the COVID-19 Pandemic: A National Review, Siobhan Chloe McKay, University Hospitals Birmingham NHS Foundation Trust (Unpublished manuscript).

¹⁶ Ibid, Siobhan Chloe McKay.

¹⁷ Ibid, Siobhan Chloe McKay.

to only 7% before the pandemic, suggesting that a greater proportion of operations are happening too late due to delays caused by the pandemic.

Support and emotional well being

2.17 In March 2020, guidance was issued advising clinically vulnerable patients, including those with pancreatic cancer, to 'shield'.¹⁸ This reduced people's support networks, with 29% of respondents to a 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.

2.18 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.

3. Recommendations

3.1 The introduction of the Single Cancer Pathway in Wales and especially the National Optimal Pathway for Pancreatic Cancer¹⁹ are initiatives that we welcome and support. However, more needs to be done and we believe a focus on the following areas would support the 500 people who are diagnosed with pancreatic cancer in Wales each year.

Diagnosis

3.2 First, we need a concerted focus on diagnosis. The Welsh Government's work so far on Rapid Diagnostic Centres (RDCs), a powerful tool especially for cancers characterised by vague symptoms, is hugely important. It must continue. Pilots in Wales have shown that RDCs are a cost-effective solution to improving outcomes for people with non-specific symptoms - indeed, a pilot in Port Talbot Hospital Wales found that RDCs reduce the average time to diagnosis from 84.2 days in usual care, to 5.9 days if a diagnosis is made at the RDC. These are excellent outcomes which must be recognised in a detailed, fully

¹⁸ <https://www.bbc.co.uk/news/uk-wales-51995997> March 2020

¹⁹ [https://collaborative.nhs.wales/networks/wales-cancer-network/wcn-documents/clinician-hub/csg-pathways-and-associated-documents/ugi-nop-pancreas-pdf/#:~:text=The%20NHS%20Wales%20National%20Optimal,suspicion%20\(PoS\)%20of%20cancer.](https://collaborative.nhs.wales/networks/wales-cancer-network/wcn-documents/clinician-hub/csg-pathways-and-associated-documents/ugi-nop-pancreas-pdf/#:~:text=The%20NHS%20Wales%20National%20Optimal,suspicion%20(PoS)%20of%20cancer.)

funded plan for rolling out RDCs further to reach people in every part of Wales. In England, the NHS has committed to rolling out an RDC in every Cancer Alliance – we need a similar commitment in Wales.

- 3.3 As mentioned above, the National Optimal Pathway for Pancreatic Cancer is welcomed- and much needed for pancreatic cancer. However, we would want the pathway to go much further, specifically recognising the aggressive progression of pancreatic cancer. 28 days is not quick enough. We need a pathway for pancreatic cancer that matches the pace of the pathway to the progression of the disease and not one with an arbitrary target that is too slow for pancreatic cancer and how quickly it progresses.
- 3.4 We believe that having a pancreatic cancer pathway from the point of suspicion/referral to diagnosis to 14 days is possible with: i) well-coordinated multidisciplinary care teams between all NHS levels ii) roll-out of rapid diagnostic centres (see below) and iii) implementation of one-stop clinics for further diagnostic tests, interventions and assessments.
- 3.5 Lung and prostate cancer both started out with 28-day pathways which have now been optimised to 14 days, showing that it is possible with the right investment and capacity.
- 3.6 The GP gatekeeping model, by design, controls and restricts access to onward referral for cancer. We know that many people with pancreatic cancer have multiple GP appointments before referral, leading to a long primary care interval and creating delays before a person is on a referral pathway. While rapid diagnostic pathways will act to increase the speed from referral to diagnosis, to reduce the primary care interval and get more patients diagnosed earlier, we need to see better awareness of pancreatic cancer in primary care, investment in innovative decision/triage support tools to help GPs have more confidence to refer higher risk patients and opportunities for patients to self-refer into RDC pathways where appropriate.
- 3.7 Crucially, investment must be targeted towards improving early diagnosis and this is made a focus of future work on pancreatic cancer. The importance of developing biomarkers and a crucial 'simple test' for pancreatic cancer cannot be overstated and is an essential building block of improving survival in this country. To back this up, there must be a focus on improving primary and secondary care professionals' decision-making tools to ensure that patients are receiving optimal care and treatment and there is consistency in approach, regardless of geographical or clinical settings.
- 3.8 Symptom awareness is also an important tool for early diagnosis of pancreatic cancer. A national awareness campaign, focussing on pancreatic cancer symptoms specifically, would encourage more patients to present early and therefore begin the journey to receiving a diagnosis sooner, improving their survival chances.

Supportive care

3.9 A common patient-reported impact of the pandemic was receiving insufficient information on a range of support from treatment and symptom management to palliative care. It is hugely important, therefore, that people with pancreatic cancer receive the appropriate support throughout their journey if we are to drive up survival rates. Factors such as nutritional support are essential to effective treatment of pancreatic cancer and to securing the best possible outcomes. We advocate that all pancreatic cancer patients need access to a dietitian and specialist CNS to receive support with symptoms and psychological and nutritional management.

Data

3.10 Secondly, we need data to paint a clearer picture of how services are currently performing, and to help us understand where the biggest issues are. Unfortunately, this data isn't currently available. The quality of data generated through the Single Cancer Pathway must improve, including breaking down waiting times by cancer type. Data would help Wales to set ambitious yet achievable targets, including a much-needed specific target for pancreatic cancer.

Appropriate resourcing of workforce

3.11 Underpinning all of this needs to be a skilled and well-resourced cancer workforce. The NHS in Wales was already short of cancer specialists before the pandemic began, and now a further reduced and exhausted workforce faces a long road back to normality. The workforce needs both restoration and further expansion to ensure people with cancer get the support they need over the coming years. We need a detailed plan setting out how the Welsh Government will recruit and skill-up their workforce so that both patients and health professionals themselves have the best possible experience of cancer care in Wales.

4. About Pancreatic Cancer UK

4.1 Pancreatic Cancer UK (PCUK) is the UK's leading charity for people living with and affected by pancreatic cancer. Our Support Line and dedicated team of specialist nurses provide expert, personalised support and information to patients and families across the country. We are also the UK's leading funding specialists into pancreatic cancer research, driving innovative research to find breakthroughs that will change how we understand, diagnose and treat pancreatic cancer. Together, we are taking on pancreatic cancer to transform care, treatment and survival for people affected by the deadliest common cancer.