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Scotland cancer strategy: consultation

Response from Pancreatic Cancer UK

June 2022

1a. What are the most important aspects of the cancer journey you would like to see included in a long-term strategy?

Think about, for example, prevention, screening, diagnosis, treatment, support for people with or affected by cancer, other care.

The most important aspects of the cancer journey for those with pancreatic cancer, which must be addressed in a long-term strategy, are diagnosis, treatment, supportive care and research.

Diagnosis
For people with pancreatic cancer, the most important part of the cancer journey is undoubtedly diagnosis. Only 17% of people with pancreatic cancer in Scotland are diagnosed at stage 1 and 2. This is the biggest driver of current low survival rates, with five-year survival currently only 5.6% in Scotland, meaning that Scotland ranks 35th out of 36 countries with comparable data in CONCORD-3. As such we need a specific focus within this strategy to ensure earlier diagnosis for pancreatic and the other less survivable cancers.

Treatment
For those who are diagnosed sufficiently early for treatment we need to ensure patient-centred treatment and care pathways for people with cancer. Currently only 30% of people with pancreatic cancer get any treatment at all, with 10% able to have potentially curative surgery. This means that when treatment is possible it's all the more important that it is timely and efficient, and that the possible impacts and prognosis are fully explained to the patient beforehand so that they can make an informed-decision about their treatment.

Supportive care
People with pancreatic cancer, and their family and carers, must receive tailored, holistic care including appropriate provision of psychological support, and signposting to patient support organisations such as Pancreatic Cancer UK, from the point of diagnosis. Recognising and managing psychological distress is particularly important for pancreatic cancer patients, as they are at higher risk of suicide than other cancer patients especially in the initial 6 months post-diagnosis but continuing up until 3 years post-diagnosis. This should be provided in line with the recently published Psychological Therapies and Support Framework for people affected by cancer.

Research
Research is crucial for pancreatic cancer and should form an integral part of the new cancer strategy. Successive governments, strategies and plans have consistently missed the opportunity to invest in pancreatic cancer research to the extent required to transform survival. Despite being the deadliest common cancer, pancreatic cancer receives only a fraction of the funding of cancers with similar case numbers, such as leukaemia (which has received four times the funding of pancreatic cancer since 2002). This has created a precarious research environment for the disease, which inadvertently discourages researchers from undertaking innovative research – but this is essential if we are to make the breakthroughs we desperately need in this cancer.

1b. Are there particular groups of cancers which should be focused on over the next 3 or 10-years?

Examples of groups may include secondary cancers or less survivable cancers.

Pancreatic cancer, and the other five least survivable cancers – lung, brain, oesophageal, liver and stomach – together are responsible for 44% of all deaths from common cancers in Scotland, and make up a quarter of cancer cases. People diagnosed with these cancers have a shockingly low life expectancy – on average, five-year survival is just 16%. People diagnosed with less survivable cancers are also much more likely to be diagnosed in an emergency setting, such as through an emergency referral or in A&E. It's therefore very important that this cancer strategy has a focus around less survivable cancers – focussing on early and faster diagnosis, and optimal pathways for individual cancers which avoid delays.

For pancreatic cancer especially, the survival gap is stark: survival rates have barely improved in fifty years. It remains the case that 1 in 4 pancreatic cancer patients die within a month, and that 93% die within five years. To improve outcomes for this cancer it is essential that it receives due focus within the new cancer strategy. Improving outcomes for the poorest performing cancers will raise the national bar, helping to improve treatment, care and survival outcomes across the board.

1c. What do you think we should prioritise over the short-term?

Consider what needs addressed within the first 3 years.

In the short term, it should be a priority to:

- Address the late diagnosis of pancreatic and other less survivable cancers, as outlined in our response to question 15a below.
- Address the current pathway for pancreatic cancer, in particular the first six weeks of the pathway. Whilst we support the existing commitments around pathway improvement, made as part of the pathway improvement project for pancreatic and liver cancers, the end of the patient pathway should also be carefully considered to ensure there is no gap between tertiary and community care in particular for palliative patients.
- Address data disaggregation and improvement as per the guidance given in our answer to question 13b below.
- Implement pre- and rehabilitation for pancreatic and other cancer patients. The guidance ‘Key Principles for Implementing Cancer Prehabilitation across Scotland’ was recently published and this should be implemented urgently and made a standard of care for pancreatic cancer by 2025, with all patients having access to a personalised programme whether or not they receive treatment by 2032. For pancreatic cancer patients, quickly accessing this kind of before and after support is especially crucial because the progression of the disease and its impact can otherwise mean that people rapidly become too unwell to have treatment, impacting on quality of life and life expectancy. Having a prehabilitation programme in place as soon as possible for people with a cancer such as pancreatic can keep people as well as possible for as long as possible, with rehabilitation dovetailing into this to maintain a quality of life whether or not recovery is an option.
- Address low Pancreatic Enzyme Replacement Therapy (PERT) prescription rates through the creation of a Quality Performance Indicator (QPI), which will address the inequalities in prescription between those who are treated within specialist centres and those who are discharged back into the community.

2a. Do you agree with a 10-year high-level strategy which will be underpinned by three shorter-term action plans?

Yes. A 10-year strategy will provide space for the ambition needed to transform survival for pancreatic and other less survivable cancers. Within a 10-year period we can plan for and deliver transformational activities for people with these cancers. However, we will need to ensure that we build regular opportunities into this period to reflect on progress and adjust the course of the plan if the required improvements are not being seen, or if adjustments are otherwise needed. Patients, patient advocates and the charity and voluntary sector must be an integral part of this regular review process.

3a. Do you agree with the below vision?

“A compassionate and consistent cancer service, that provides improved support, outcomes and survival for people at risk of, and affected by, cancer in Scotland”

Yes - compassion and consistency are key in providing care. An addition of ‘holistic’ / ‘patient-centred’ would be welcome in this vision, as well as referencing the need for improvements at every step of the journey. Patients whose cancer is terminal and untreatable should be treated with particular compassion and consistency, and reflecting this in the vision would also be welcomed – so that no cancer patient feels abandoned in the case of having terminal cancer.

4a. Do you agree with the below goals?

- *Slowing down the increasing incidence of cancer*
- *Earlier stage at diagnosis*
- *Shorter time to treatment*
- *Lower recurrent rates*
- *Higher survival rates*
- *High quality, consistent experience of the health service for people affected by cancer g) An enabling environment for research and innovation in diagnosis and treatment*
- *Reduced inequalities in all these areas]*

Yes, but the addition of a point around addressing disparities between cancer outcomes, as not all cancers are equal in threat/outcomes would be welcomed. For example, less survivable cancers (pancreatic, brain, lung, liver, stomach, oesophageal) time to treatment needs to be prioritised as performance status can deteriorate quickly.

An additional aim around increased screening and surveillance availability would also be welcomed, as well as a point around improved and increased data collection.

5a. Do you agree with the below principles?

- *putting patients at the centre of our approach*
- *actively involve communities and users of services*
- *be inclusive*
- *provide high quality, compassionate care*
- *ensure services are sustainable*
- *collaborate across all sectors*
- *use an evidence-based approach and make the best use of emerging data/ research/ technology*
- *strive for consistency through a 'Once for Scotland' approach*

These principles are good, but should also include reference to supporting family and carers. This is especially important for cancers such as pancreatic where deterioration is often very quick and outcomes are poor as it's important here to involved loved ones in care and decision-making wherever possible.

These principles should also be updated to mention the importance of a whole-team approach in order to provide high-quality, compassionate care.

6a. Do you agree with the below themes?

- *Person-centred care*
- *Prevention*
- *Timely access to care*
- *High quality care*
- *Safe, effective treatments*
- *Improving quality of life and wellbeing*
- *Data, technology and measurement*
- *Outcomes*

Yes, we support these broadly; however, it is important that the theme 'improving quality of life and wellbeing' should also explicitly include people who are palliative, as this is not currently always the case. We hear from people with pancreatic cancer who sometimes feel 'written off' if they are palliative, and are not receiving the holistic, compassionate care they should be. Scope for the cancer strategy must extend to actively ensuring that high-quality, supportive care is given to those for whom cure is not an option.

Person centred-care

7a. Do you agree with the below areas of focus for the theme of person-centred care? What aims or actions would you like to see under any of these areas?

- *Individual experience (by responding to Scotland Cancer Patient Experience Survey 2022 (SCPES)and by working with Third Sector and key partners on projects such as Care Opinion)*
- *Co-production of some actions with people affected by cancer*
- *Wider support for people living with and beyond cancer and their supporters (for example Single Point of Contact, Transforming Cancer Care, Prehabilitation)*

Specific consideration must be given to people who are diagnosed with an incurable or less survivable cancer, such as pancreatic cancer. Quality of life for this cohort is especially important within the limited time they have left, and this needs to be central to the strategy's approach to person-centred care. This cohort is not insignificant; whilst people with a less survivable cancer account for around a quarter of those diagnosed, they also account for just under half of cancer deaths in Scotland.

The aims highlight the SCPES as a key method of monitoring patient experience; however, this currently inadvertently excludes patients because there will be a roughly six-month gap between their discharge and receiving the survey. In this time many people who have a less survivable cancer, such as pancreatic, will have unfortunately died (half of patients with pancreatic cancer die within three months). As such it's essential to broaden patient monitoring further, and use more innovative methods, so as to collect data from these patients whose experience is of the utmost importance given the limited time they have remaining.

Palliative care should also be included as a key part of these aims to ensure that specific attention is given to this, as these patients are all too often insufficiently supported post-discharge.

Timely access to care

9a. Do you agree with the below areas of focus for the theme of timely access to care? What aims or actions would you like to see under any of these areas?

- *Screening (such as national programmes and genetics)*
- *Early detection and diagnosis (looking at genetic tests/molecular pathology; diagnostic tests (haematology, pathology, radiology, endoscopy); Detecting Cancer Early programmes; and Early Cancer Diagnostic Centres)*
- *Primary Care (including direct access to investigations, referrals and opinions; and education and engagement with communities)*

Yes, we broadly agree with this. We would like to see the following actions in this area to address pancreatic cancer specifically, as it has the lowest early-stage diagnosis of all common cancers, with 3 in 5 people in Scotland being diagnosed at a late stage where curative surgery is unlikely to be possible. Further, almost half (44%) are diagnosed through emergency presentation, demonstrating the need for tailored action to achieve early diagnosis for pancreatic cancer.

Screening and surveillance:

Screening is hugely important for pancreatic cancer. About 10% of total pancreatic cancers are hereditary. However, there is not currently provision for surveillance of those at risk of hereditary pancreatic cancer through the NHS. Surveillance is only given through research studies such as the EUROPAC study in Liverpool. This is a considerable limitation as not all people at risk across the country are offered screening, despite the recommendation included in the NICE guidance on diagnosis and management of pancreatic cancer in adults (NICE NG85).

As such, the Government should start working closely with EUROPAC to better understand the risk of familial pancreatic cancer, and must commit resource and funding to ensure that everyone at risk of familial pancreatic cancer has access to a surveillance service through the NHS, no matter where they live in Scotland, by 2024.

As well as this, emerging evidence demonstrates that a new diagnosis of pancreatitis with unknown cause, history of chronic pancreatitis with increasing pain, weight loss and jaundice, and New-Onset Diabetes, are also risk factors for developing pancreatic cancer. Further funding commitments to surveillance programmes are needed for people at risk of pancreatic cancer so that everyone at risk has access to a surveillance service by 2032. Specific studies will also help us to understand the best approach to identifying and providing surveillance to at-risk groups, and should be undertaken by 2026, with full implementation of learnings by 2032.

Primary care:

Scottish Government should invest in the development of a triage biomarker test for pancreatic cancer in the next 2-3 years, so that by 2032 every patient with pancreatic cancer can receive a prompt referral to be diagnosed at an early symptomatic stage by the GP. Tools such as the QCancer will help to better pick up those with suspected symptoms of pancreatic cancer for referral. QCancer has been designed with the aim of developing machine learning tools to identify combinations of symptoms in health records which generate a risk score and a red flag for pancreatic cancer. We also need to see investment in innovative biomarker research to develop a triage test to help identify those who should be referred for investigation by 2026.

Awareness:

Pancreatic cancer normally causes vague and non-specific symptoms, it lacks a simple test for detection and there is poor public awareness of the symptoms (a quarter of people in Scotland would wait three months or more to seek help from their GP if they had potential symptoms of pancreatic cancer, and two thirds of UK adults say that they are not aware of the symptoms). As a result, it remains exceptionally difficult to diagnose at an early stage, making pancreatic cancer almost impossible to treat and survive for the majority. This leads to shocking outcomes: over half die within three months of diagnosis.

A campaign focussed on pancreatic cancer has the potential to save lives through earlier diagnosis and we urge the Government to invest in this. Success has been seen in other cancer types: a national Be Clear on Cancer campaign in England for lung cancer symptoms increased the number of people diagnosed with lung cancer, increased the proportion of people diagnosed at an early stage and of people receiving surgery. Results show there were an estimated 700 additional cancers diagnosed in the months surrounding campaign activity, compared to the same period in the previous year.

Diagnosis:

NHS in Scotland are currently developing a Pancreatic Cancer Improvement Project, in partnership with the Scottish Hepato-Pancreato-Biliary Network looking at the first six weeks of the patient pathway. We greatly welcome it and are keen to lend our expertise to support its continued development.

With regards to referral; the central reason for the low early-stage diagnosis in the UK compared to other countries is the primary care ‘gatekeeping’ system, rather than differences in public awareness of symptoms across developed countries. The propensity to refer from primary care is influenced by a combination of system-wide factors, including the Scottish Referral Guidelines for Suspected Cancer. These criteria do not pick up people with pancreatic cancer quickly or effectively and they should be broadened to include:

- Consideration of referral with a broader combination of persistent unexplained symptoms, including but not dependent on weight loss
- Referring people for pancreatic cancer if they have jaundice at any age
- Broader and more flexible referral of people with new-onset diabetes in combination with another symptom.

High quality care

10a. Do you agree with the below areas of focus for the theme of high-quality care? What aims or actions would you like to see under any of these areas?

- *Workforce (thinking, for example, about requirements and modelling for oncology and other workforce, including specialist nurses; leadership)*
- *Service delivery (thinking about national, regional and local services; flexible use of workforce; role of cancer network; strategic alliances and working across health boards, for example)*
- *Inequalities (thinking about how to make sure everyone is included, and targeting those who may be at a disadvantage)*
- *Accessibility (breaking down barriers such as geographical, cultural or language)*
- *Integrated support services between NHS and Third Sector*

Yes – we agree broadly with these themes. However, the Government must ensure that by 2032, pancreatic cancer workforce numbers are stabilised and increased so that everyone with pancreatic cancer has access to specialist clinical and allied professional support.

With regards to inequalities, preliminary data suggest inequalities in the care and treatment of operable and inoperable patients; incidence rate is higher in Black populations as opposed to White populations; and the risk of emergency diagnosis is higher in deprived communities. More and better data must be collected to give us greater understanding of these problems in order to address them.

The resource-poor health system can limit CNS’ opportunities to fully support patients psychologically, but where possible they should be encouraged to prioritise patients’ welfare and engage in further training around managing patients’ mental health.

We need to retain and recruit more HPB and UGI CNSs to ensure this support can be provided. Similar prioritisation needs to be done with other specialist members of the cancer workforce that provide supportive care, such as dieticians, who have the potential to have a significant impact on patients’ quality of life. Greater dietician resource would also benefit other cancer patients, such as oesophageal, stomach, bowel and throat amongst others.

The third sector is integral to cancer patient support as well as supporting the learning and development of healthcare professionals, for example through the creation of training by charities such as Pancreatic Cancer UK’s training on Pancreatic Enzyme Replacement Therapy.

Currently, hundreds of healthcare professionals across the UK have undertaken Pancreatic Cancer UK's dedicated training on PERT and on pancreatic cancer more generally, but the numbers who have taken this training within Scotland remain low. Government should work with Pancreatic Cancer UK and the wider charity sector to develop CPD partnerships between NES/NHS Academy and the charity sector. We are providing peer reviewed, endorsed training on areas such as PERT, which could be accessed by Health Professionals through the TURAS platform.

Safe, effective treatments

10a. Do you agree with the below areas of focus for the theme of safe, effective treatments? What aims or actions would you like to see under any of these areas?

- *Surgery*
- *Radiotherapy*
- *Systemic anti-cancer treatment*
- *Acute oncology*
- *Realistic medicine*
- *Consent*

For pancreatic cancer, Scottish Government should fully implement the Optimal Care Pathway currently being developed by Pancreatic Cancer UK with leading clinicians, to eliminate variation and standardise care across Scotland.

People with pancreatic cancer should be assigned to pancreatic cancer-specific prehabilitation and rehabilitation programmes to optimise access and tolerance of treatment through a joint approach of physical activity, nutritional optimisation, symptom management and psychosocial support.

Enhanced Recovery After Surgery (ERAS) principles should be used as standard in the context of pancreatic surgery, and it should be ensured that systems have sufficient resource to enact them fully by 2032.

Optimal Care Pathway:
Pancreatic Cancer UK, working with lead clinicians in the field across the UK, has developed an Optimal Care Pathway, from symptom presentation to diagnosis and access to best treatment and supportive care. The Government must ensure that this Optimal Care Pathway is adopted by NHS in Scotland so that everyone, from doctors and nurses to patients and their families, know what to expect and what should happen to give people the best possible chance of survival. Specific, regularly reported KPIs should also be adopted to track and reduce variation alongside the annual repetition of a pancreatic cancer audit.

SACT / Surgery:
Surgery is the only curative treatment for pancreatic cancer. Currently 70% of people with pancreatic cancer do not receive any type of active treatment such as surgery or chemotherapy – even those who are diagnosed early. A major factor driving poor treatment access in pancreatic cancer is the aggressive and fast deteriorating symptoms of the disease. This is why it is critical for people with pancreatic cancer are expedited onto pre- and rehabilitation programmes. Equally, ERAS should be made standard of care to facilitate optimal recovery from surgery where it is possible.

Quality of life and wellbeing

12a. Do you agree with the below areas of focus for the theme of improving quality of life and wellbeing? What aims or actions would you like to see under any of these areas?

- *Prehabilitation and rehabilitation*
- *Psychological support*
- *Patient pathways (including quality of care, waiting times, less survivable cancers)*
- *Palliative medicine, Best Supportive Care and End of Life care*
- *Support to family/carers*

Yes. Recognising and managing psychological distress is particularly important for pancreatic cancer patients. They are at higher risk of suicide than other cancer patients, especially in the initial 6 months post-diagnosis but continuing up until 3 years post-diagnosis. Given the progressive nature of the illness, all pancreatic cancer patients should be promptly assessed and provided with psychological support if required.

Scottish Government must ensure that by 2032 everyone with pancreatic cancer receives tailored, holistic psychological support for pancreatic cancer patients, from the point of diagnosis through to living with cancer, or best supportive care.

We welcome the recently published Psychological Therapies and Support Framework for people affected by cancer and would urge that healthcare professionals consider that such interventions be delivered in a variety of settings, including both local and national charities. It is also important to support patient carers to understand that biological factors relating to pancreatic cancer can present as depression.

People with pancreatic cancer should be prescribed Pancreatic Enzyme Replacement Therapy (PERT) as standard, and Scottish Government should introduce a national PERT target through a Quality Performance Indicator (QPI) in the 2022 QPI review, to consolidate and track progress of the recent commitments made on PERT and ensure a ‘Once for Scotland’ approach. Currently, PERT is only prescribed to 1 in 3 pancreatic cancer patients in Scotland, and further, is more likely to be prescribed to those who are treated within a specialist setting than to those who are treated within a general or community setting.

The transition and communication between secondary, tertiary and primary care should be carefully managed where cure is not an option.

Signposting of patients to patient support organisations such as Pancreatic Cancer UK must also be improved, and links between the third sector should be formalised and strengthened. This can be facilitated by a key worker whose roles includes formulating these links between patient and support.

Care should also be taken by healthcare professionals to have an overarching discussion with patients about their treatment options, and discuss the option of having no treatment where this is relevant. It is crucial that patients’ quality of life is balanced with outcomes and survivability chances in the instance of late-stage cancer. Discussions about this should be normalised and standardised, and family should be involved in them wherever possible.

Patients should be provided with access to information and support through follow-up wherever possible, in order to help patients retain as much knowledge as they can post-appointment when they are more likely to remember it than if they are overwhelmed with information during the appointment.

Existing commitments around pathway improvement, made as part of the pathway improvement project for pancreatic and liver cancers, should be tested, adopted and embedded in a once for Scotland approach. Whilst we agree that the first six weeks of the pathway especially should be addressed, the patient pathway following diagnosis should also be carefully considered. Management and support of patients as they move out of tertiary care – in particular for palliative patients – is crucial, and patients must continue to receive thorough support post-discharge from hospital (especially in palliative scenarios).

12a. Do you agree with the below areas of focus for the theme of data, technology and measurement? What aims or actions would you like to see under any of these areas?

- *Outcomes e.g. recurrence, benchmarking*
- *Scottish Cancer Registry and Intelligence Service (SCRIS)*
- *Quality Performance Indicators (QPIs)*
- *Cancer Waiting Times (CWTs)*
- *Cancer Medicines Outcome Programme (CMOP)*
- *Patient Reported Outcome Measures (PROM)*
- *Multi-disciplinary teams (MDTs)*
- *Research, technology and innovation (including regulation/quality/safety)*
- *clinical trials/ precision medicine/ genetics/ genomics/ molecular pathology (screening, diagnostics, treatment)*
- *robotics-health, for example, Near Me and Connect Me*

Yes – however changes must be made to improve data collection and disaggregation in order to give us vital intelligence in driving improvements, including:

- HPB cancer waiting times operational standards must be disaggregated to individual cancer types and also grouped by treatment intent, such as active treatment (curative or palliative) and other care (e.g., supportive care)
- Pancreatic cancer data should be broken down to exocrine PDAC and endocrine PNET, as part of the national cancer datasets routinely collected
- Implement a CWT standard from urgent referral to definitive diagnosis, aligned with the Faster Diagnostic Standard (FDS) in England, to more accurately measure and assess the speed of patients' diagnostic experience.
- The 31-day CWT from decision to treat to first treatment should be revised to be faster than 31 days, or at least have a faster target for cancers with rapid progression and where it is clinically appropriate to act urgently.

Currently, there is some staging and treatment information provided through the SHPBN HPB audit, however, it would be better for complete national staging and treatment data to be published routinely.

Therefore, to give a complete picture of cancer in Scotland, there should also be national and health board data routinely published for:

- Staging data for each tumour type (staging data only currently available for breast, colorectal and lung through Detect Cancer Early)

- treatment data for each tumour type (chemotherapy, radiotherapy, surgery, other care etc.)
- Survival by stage for each tumour type
- Routes to diagnosis for each tumour type.

Research funding in the next two years should be increased to identify, image and monitor those at increased risk of pancreatic cancer with the aim of a pancreatic cancer screening programme to be nationally rolled out by 2032.

This can be done through the development of machine learning tools and targeted interventions to identify people in GP records with a combination of symptoms, conditions and risk factors that are associated with a high risk of developing pancreatic cancer, which could then lead to a referral or follow up survey to further enrich these population data. This could start by targeting patients with new-onset diabetes (NOD), given the high risk associated with pancreatic cancer in people with NOD: it can be detected in the pre-symptomatic phase and is one of the most promising risk factors that could enable earlier diagnosis. At the time of diagnosis, around 65% of people with pancreatic cancer have diabetes, with more than 50% having new-onset diabetes.

Assuming research funding should be commensurate with the number of deaths in the population due to that cancer, we recommend investment should be increased to bring spend in line with the other four biggest causes of cancer-related death.

Research partnerships should be built and strengthened. Government should invest in building partnerships between members of the detection research community in pancreatic cancer, and experts in the field of implementation research. This could be achieved through schemes that bring together and award funding specifically to multi-disciplinary research teams seeking to ensure that innovations in detection can be seamlessly adopted by NHS cancer pathways. These formats have already been used successfully in the cancer detection space. Additionally, the Government should provide the research community with networking and engagement opportunities to ensure a balance in outcomes and economics of detection innovations, increasing the pace and efficiency of their transition out of the lab and into the clinic.

13b. Is there any technology that you would like to see introduced to improve access to cancer care?

Please consider access to screening, diagnostics, results, tracking of your pathway.

We want to see greater roll-out of e-health interventions, such as giving patients access to online appointments and support. This is especially important for pancreatic cancer patients because they are often diagnosed late and deteriorate very quickly. Extensive travelling for consultations - which is especially an issue for people in rural Scotland – can be avoided in some cases if these options are more widely available.

We would urge experience and outcome measures to be prioritised similarly to other measures, including through the scaling up of PROMs and PREMs. The data and insights from these measures must be intrinsically linked with QPIs to holistically measure improvements within cancer services.

Overall funding should be increased for pancreatic cancer as despite being the deadliest common cancer, it receives only a fraction of the funding of cancers with similar case numbers, such as leukaemia (which has received four times the funding of pancreatic cancer since 2002 across the UK). This has created a precarious research environment for the disease, which inadvertently discourages researchers from undertaking innovative research – but this is essential if we are to make the breakthroughs we desperately need.

14. What suggestions do you have for what we should measure to make sure we are achieving what we want to in improving cancer care and outcomes?

The Scottish Cancer Patient Experience Survey currently has a survivability bias towards patients who survive longer; patients with pancreatic cancer will often die too quickly to be effectively captured and surveyed. We need to make changes to ensure that these patients have the opportunity to share their experiences and feedback in a meaningful and timely way.

A Cancer Waiting Time standard should be implemented from urgent referral to definitive diagnosis, aligned with the Faster Diagnostic Standard (FDS) in England in order to more accurately measure and assess the speed of patients' diagnostic experience.

Scottish Government should introduce a national Pancreatic Enzyme Replacement Therapy (PERT) target through a Quality Performance Indicator (QPI) in the 2022 QPI review, to consolidate and track progress of the recent commitments made on PERT and ensure a 'Once for Scotland' approach. Currently, PERT is only prescribed to 1 in 3 pancreatic cancer patients in Scotland, and further, is more likely to be prescribed to those who are treated within a specialist setting than to those who are treated within a general or community setting.

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- treatment data for each tumour type (chemotherapy, radiotherapy, surgery, other care etc.)
- Survival by stage for each tumour type
- Routes to diagnosis for each tumour type.

15a. What would you like to see an Earlier Diagnosis Vision achieve?

Think ahead to the next 10 years, think big picture – what change(s) should we be aiming to influence when it comes to earlier cancer diagnosis? Consider access to care/cancer screening/primary care/diagnostics and awareness of cancer signs and symptoms.

Scottish Government should invest in the development of a triage biomarker test for pancreatic cancer in the next 2-3 years, so that by 2032 every patient with pancreatic cancer can receive a prompt referral to be diagnosed at an early symptomatic stage by the GP.

Research funding should be increased over the next two years to identify, image and monitor those at increased risk of pancreatic cancer with the aim of a pancreatic cancer screening programme to be nationally rolled out by 2032.

Capacity and workforce should be provided to implement the Pancreatic Cancer Pathway Improvement Project after its pilot phase, should it achieve its aims to shorten diagnosis times and first treatment to day 41/42. This centralised approach should be considered for other lower volume, less survivable cancers.

The scope of the Scottish Referral Guidelines for Suspected Cancer should be expanded. These criteria do not pick up people with pancreatic cancer quickly or effectively and they should be broadened to include:

- Consideration of referral with a broader combination of persistent unexplained symptoms, including but not dependent on weight loss
- Referring people for pancreatic cancer if they have jaundice at any age
- Broader and more flexible referral of people with new-onset diabetes in combination with another symptom.

15b. Should the Earlier Diagnosis Vision set itself a numerical target?

A specific target for pancreatic cancer and less survivable cancers would be greatly welcomed and would help to accelerate much-needed improvements in early diagnosis for these cancers. We would like to see a 50% target for diagnosis of pancreatic cancer at Stage 1 and 2 in particular.

15c. Should the earlier cancer diagnosis vision focus on specific cancer types?

Pancreatic cancer requires specific focus within this strategy. Currently, only 16% of people with pancreatic cancer are diagnosed at stage one or two – the key reason behind pancreatic cancer's poor survival statistics, as the later people are diagnosed, the later their chances of being able to receive potentially curative surgery.

More broadly, there should be a specific focus on the less survivable cancers – pancreatic, brain, lung, liver, oesophageal and stomach – as these account for a quarter of Scottish cancer diagnoses but half of all Scottish cancer deaths and outcomes for these cancers are generally much poorer than for other cancers. As such they need specific focus in order to improve outcomes and close the cancer survival gap between these and other cancers.

15d. If you or a family member or friend have previous experience of a cancer diagnosis, where did the service work well and why was that? What could have improved the experience?

Please refer back to your personal experience to identify how services worked well and where improvements could be made.

We surveyed 50 members of our engaged Scottish community about their, or their loved one's experience of getting treatment for pancreatic cancer. The commonly emerging themes are outlined below.

What worked well:

- **Sometimes quick onward referrals**
    - “We were extremely fortunate that it was pre-pandemic and that our GP knew him well, treated him sensitively, and referred him to hospital without wasting any time” Liz, Achnasheen
    - “As a result of getting a quick referral and early diagnosis I was able to have surgery and chemo. I have now been given the all clear and I am sure this was due to my early diagnosis.” Susan, Inverness
- **Quick diagnostic tests**
    - “The emergency liver service at Ninewells hospital were great in getting my husband seen quickly and arranging diagnostic scans etc.” Sandra, Forfar
    - “The hospital consultant was equally good and tests, scans, etc were carried out timeously.” Alexander, Cumnock
- **Once diagnosed, care was excellent**
    - “Once diagnosed the care from the mdt and the Beatson was excellent.” Iain, Glasgow
- **Benefits system was joined-up well**
    - “Benefits system kicked in early when diagnosis terminal - [it’s] so important for families not to worry about finances at this time.” Fiona, Edinburgh
- **Follow-up appointments and scans after surgery**
    - “Diagnosis, operation and follow up. As I understand it follow up from a successful operation is now minimal. My 4th follow-up appointment 2 years after my operation discovered a recurrence of my cancer which, if not detected would have been more serious than my original diagnosis. So improvements to follow up and follow up scanning is required urgently.” Steve, Skelmorlie

What didn’t work well:

- **Disjointed communication between different teams – e.g. hospital, GP, community care, hospice**
    - “Once diagnosis and chemo started there was very disjointed communication between Oncology/chemo unit and GP which made things more difficult and frustrating than they should have been.” Sandra, Forfar
    - “The Beatson Hospital thought the Hospice in Ayr was looking after her and the Hospice thought the Beatson was caring for her. In fact, no one was caring. They need to speak better to each other.” Alexander, Cumnock
- **Lack of GP awareness of symptoms of pancreatic cancer and lack of action on symptoms e.g. stomach/back pain, weight loss, new-onset diabetes**
    - “GP failed to take matter seriously and undertook no tests or checks.” Carol Ann, Glasgow
    - “GP missed red marker for cancer so results filed and patient assumed no concerns.” Fiona, Edinburgh
- **Waits for diagnosis**
    - “The length and inexperience until diagnosis is severely wanting and needs to be addressed.” Iain, Glasgow
    - “Unfortunately the service only worked well AFTER my wife was diagnosed with terminal pancreatic cancer. From having stomach pains around September 2019, it took until December 2019 to get her tragic diagnosis, after which she declined and passed in June 2019 at the tender age of 64. Who will ever know if a few months' time had been saved through earlier diagnosis, if it would have made any difference in our case.” Colin, Aberdeen

- **People felt abandoned and lost post-treatment and when they were discharged:**
    - "Once my treatment was done, I felt a little lost, as all the energy is put into getting you through treatment, which is absolutely needed but help could be given afterwards, which shouldn't just be down to charities." Donna, Dalkeith
    - "I feel abandoned by everyone apart from my family and am dealing with everything without the required support from consultant or GP." Julie, West Dunbartonshire
    - "When he was in hospital, he received great care but when there was nothing more they could do and he came home, the care package was not good." Fiona, Linlithgow
- **Not enough support with digestive symptoms and dietary issues**
    - "Limited help with diet - drink supplements." Elizabeth, Gairloch
- **Dismissal of people who don't fit the 'typical' age criteria for pancreatic cancer**
    - "[GPs need to realise] that a young person might have the disease, and not just dismiss a so-called cyst as irrelevant. I lost a twenty-seven-year-old son, who was also a father, partner brother, it goes on. Devastated our lives." Shirley, Shotts
- **People feeling that they didn't realise sufficiently high quality of care**
    - "More training in cancer care for doctors and nurses and better staffing levels." Angela, Elgin

Additional points to note:

- For people with pancreatic cancer, waits until diagnosis can be a death sentence, as the quick progression of this cancer means that only 1 in 10 are diagnosed early enough to be eligible for curative surgery.
- People with pancreatic cancer are not getting sufficient information and support to deal with dietary issues and digestive symptoms. This is especially the case with regards to information and advice on taking Pancreatic Enzyme Replacement Therapy (PERT). Far too many patients have been given inaccurate information on how, and how much, to take – yet PERT can greatly improve people's quality of life and even help people build and maintain the strength they need to undergo curative surgery.

15e. From your previous experience where would you like to access care if you had concerns about cancer that would be different to what is available currently?

We surveyed 50 members of our engaged Scottish community about their, or their loved one's experience of getting treatment for pancreatic cancer.
The key themes when we asked them where they would like to access care if they had cancer concerns are below:

- **Online – support and triage; helplines**
    - "Online or on a call to a cancer charity." Liz, Achnasheen
    - "Surely the NHS now has the capacity to look at initial online triage which could pick up symptom clusters and allow people to get an appointment for scans and blood tests?" Alison, Glasgow
- **More support from GPs**
    - "GP was not very helpful unfortunately. Support is important within one day my husband who never had any health problems all of a sudden had gruelling chemotherapy, insulin dependent diabetes, numerous medications had I not been

  - a nurse I don't know how he would have managed but from dr/GP there was no interaction accept if we asked for it." Gail, Blantyre
  - "I feel GP or pharmacist should be available to help but they are not currently." Julie, West Dunbartonshire
- **Give patients and families more leaflets**
  - "The hospitals should have more information leaflets you give patients/family rather than having to source all that yourself during a very traumatic period" Sandra, Forfar
- **Community pharmacy/ services**
  - "Local pharmacy would be good but only if they were qualified to deal with cancer, in particular Pancreatic cancer." Isobel, Glasgow
  - "Easier access to knowledgeable health care support, whether it's the local medical Centre, or clinic specialists." Terry, Westhill
  - "I would like there to be more support in my local community." Tracy, Wigside
  - "Pharmacy would be a good start, but would be good also to have specialised nurses in the doctor's surgeries/ health centres, even if they were just there one day a week." Angie, Glasgow
- **More face-to-face support – e.g. local community, GP**
  - "Drop in sessions/ clinics held in local halls, churches. Too much time is spent online or watching screens, so face to face chats would be good." Donna, Dalkeith
  - "Doctors appointments face to face would really help out." Alexander, Cumnock
  - "[My mum] was given her diagnosis over the phone, a terminal one, by a secretary. This kind of news should be delivered by healthcare professionals in person." Caroline, Perth
- **Support from non-medical professionals**
  - "More non-medical people who can provide information and have the time to discuss it all. Doctors/ nurses don't have the time and don't have good enough communication skills" Elizabeth, Gairloch
  - "When a diagnosis of PC is given it would be wonderful if a support worker or volunteers from the charities who is trained in advising was there. They can direct the person about who to contact for advice and knowing there are qualified nurses who can answer any questions that arise when you get home and the impact of the diagnosis sinks in. When I was diagnosed with Breast Cancer within minutes there was an BC specialist nurse there to take me through the next steps. After surgery chemo and radiation there was support and meetings for how to move on with your life." Penelope, Lanark

15f. What does good earlier cancer diagnosis look like for you?

Think about what a good outcome would be, for example more people being diagnosed when they can be cured of cancer, living well with cancer for longer etc.

We surveyed 50 members of our engaged Scottish community about their, or their loved one's experience of getting treatment for pancreatic cancer.

The key themes when we asked them what good earlier cancer diagnosis would look like are below:

- **Quick access to health professionals**
  - It took my mum 6 years to be taken seriously by her GP. They need to screen for pancreatic cancer much earlier than they do. If her cancer hadn't been missed on her first MRI, she may have lived. So training is needed at all levels on what to look for." Caroline, Perth
- **Development of a blood test for pancreatic cancer**
  - "My father received yearly scans due to a previous cancer. But this still didn't catch pancreatic cancer early. I think a blood test needs to be developed to catch pancreatic cancer earlier." Tracy, Rigside
- **Fast-tracking people to surgery**
  - "The major major point with pancreatic cancer is fast track to an operation to remove it if that offers a possibility of 'cure'." Ginnie, Edinburgh
- **Expansion/ update of the referral criteria for pancreatic cancer**
  - "My view is the referral criteria needs looked at and the usage of proper diagnostic equipment as a priority. An xray is pointless for most conditions like this so why not straight to the mri or ct scan?" Iain, Glasgow
- **Quick, early testing and screening**
  - "Voluntary, early testing would definitely be a major step forward in the fight against this horrendous disease." Brian, Glasgow
  - "I know can't give an all-body scan to every adult yearly, but any upper gi/back pain that can't be easily identified or explained, [you should] refer [the patient] for ultrasound at least. Then ct scan especially if the patient isn't a frequent user of gp services. Take the pain or other symptoms seriously." Gail, Blantyre
  - "Access to self-screening and escalation to testing and scans and specialist consultancy" Alison, Glasgow
  - "For tests such as scans etc to be done all in one day, and results given that day, saving stress." Christina, Blantyre
- **Speed**
  - "Quick appointments, referrals and response from the appropriate consultants, team. Good support from trained, knowledgeable practitioners within easy distance." Alistair, Dunfermline
- **Taking time to communicate clearly and in-person with the patient, and seeing them holistically**
  - "Time with patient and their advocate/relative to explain their plan of care. Often patient on medication affecting their ability to absorb information - how patient receives information should be clear with nursing/medical staff encouraging why receiving this in presence of an advocate a good thing." Fiona, Edinburgh
  - "Listening to patients, taking their concerns seriously." Carol Ann, Glasgow

  - "A health care professional listening to the patient and seeing a whole person not a problem that can be dismissed and forgotten about. People know their own bodies and only seek a professional opinion when they are concerned. Scans X-ray etc should be organised in a timely manner not after frequent requests and visits to the surgery." Penelope, Lanark

16a. In your experience, are there aspects of cancer diagnosis, treatment or care that affect people from marginalised groups differently? If there are negative effects, what could be done to prevent this happening?

Please consider the 'protected characteristics' of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation.

Preliminary data suggest inequalities in the care and treatment of both operable and inoperable pancreatic cancer patients and incidence rate is higher in Black populations as opposed to White populations. More and better data must be collected to give us greater understanding of these problems and what causes them, in order to then act on them.

16b. Similarly, is how we manage cancer different for wealthy or poor people? What could be done to do this better?

Data suggests that the risk of emergency diagnosis for pancreatic cancer patients is higher in deprived communities. More and better data must be collected to give us greater understanding of what drives these inequalities before we can then act.

16c. Is the experience of cancer different for people living in rural or island communities? What could be done to prevent any negative impacts?

Yes – people in rural communities more often have to **travel to receive tests, treatment and surgery for pancreatic cancer**. We surveyed our supporters about how rurality impacted them, and some example answers were:

- "My friend with pancreatic cancer had to travel 200 miles to Aberdeen from Shetland for tests to commence her chemo when they lost the first set of results" Carol, Lerwick
- "I have to organise transport to hospital, 60-mile round trip which can take 3 hrs sometimes and that on top is a long difficult day" David, Dunbar
- "Definitely traveling [is an issue], lack of accessible close parking when having chemo. Visiting hours make it harder for family and close friends to travel from outside where the hospitals are based. Patients feeling isolated as hospitals are usually in cities." Penelope, Lanark
- "The service did not work well because the island nurse dismissed lack of appetite and ridiculed my mother-in-law, whose symptoms were missed, losing her valuable time before she arranged to go out of island and visit her doctor, weeks later. The community nursing service also would not talk to her family about her care whilst they were living with her. [...] Improve training in rural communities in community nursing. Prioritise cancer symptom check-ups and provide cost of associated flights. Offer an annual check-up with doctor in-island, asking cancer symptom check questions as well as blood pressure, etc." Lindsey, Inverness

Others mentioned the **need to upskill healthcare professionals in island communities** so that people don't have to travel to receive the same standard of care as those living in urban locations:

- "Everyone should have the same opportunities to get the right treatments. I am from a Scottish Island, where patients have to either fly or get a ferry to bigger hospitals to get treatment. Would you want to travel for hours feeling so ill and in pain? Of course not! Island hospitals should have medical teams and treatments coming to the patients, or at the very least, training medical staff already there! Poorly run health boards need to be scrutinised and taken to task for their failings. Patients can't afford to be waiting days or weeks, purely to get an appointment with a GP. People need help now!" Donna, Dalkeith
- "Yes, definitely different. In Shetland, patients often have to travel 200 miles to Aberdeen to receive treatment, which is either a one-hour flight or 12 hour ferry crossing. With frequent weather or technical delays, it makes an already stressful time 100 times worse. If you're having ongoing treatment you either have to be an in-patient or live in a B&B between sessions. Or do the return 200-mile journey whilst suffering the after effects of treatment. Being able to provide treatment locally would have a hugely positive impact on patients. Also more diagnosis locally, instead of having to travel for scans or tests." Carol, Lerwick
- "[People in rural communities] have even worse access to specialist consultants and specialist treatments than patients on the mainland do at the moment." Steve, Skelmorlie

The **need for financial support** for those who do have to travel to access care and support was also mentioned by some:

- "Financial support [is needed] if families having to move from one community to another due to care not available in their own community." Fiona, Edinburgh

17. What other comments would you like to make at this time?

This new strategy is an unmissable opportunity to give pancreatic cancer the attention it deserves. We strongly recommend including specific attention and action points around pancreatic cancer, as well as the six less survivable cancers (lung, liver, pancreatic, brain, oesophageal, stomach), in order to drive up survival outcomes. These have barely shifted in decades and a targeted focus on their diagnostic pathways has the potential to make a significant difference for people with these diagnoses. Getting it right for these cancers, which have the poorest outcomes, will have the knock-on effect of raising standards, and ultimately improving outcomes for all other cancers.