

Sir Simon Stevens
Chief Executive
NHS England
Skipton House
80 London Road
London SE1 6LH

Dear Sir Simon,

We are writing to share our serious concerns about the low rates of prescription of a vital medicine for people with pancreatic cancer, and to request an urgent meeting to discuss how we can work together to tackle this problem.

As you'll know, pancreatic cancer is the deadliest common cancer in the UK. Three in five people with pancreatic cancer are diagnosed at a late stage.

Most people will receive no treatment, and one in two will die within three months. These three short months are extremely distressing, with people often unable to digest their food, leading to rapid weight loss and unpleasant nutritional and digestive symptoms. But Pancreatic Enzyme Replacement Therapy (PERT), already a widely available prescription, can make a significant positive impact on the most debilitating of symptoms.

As you will know, PERT replaces the digestive enzymes that people with pancreatic cancer can no longer produce, allowing food to be digested and absorbed by the body. It helps people gain the strength to undergo treatment, and gives them a better quality of life for the precious time they have left.

Yet despite clinical consensus that PERT is crucial for people with pancreatic cancer, and 2018 NICE guidelines clearly recommending PERT for all pancreatic cancer patients, new research shows that **only 56% of people with pancreatic cancer in England are being prescribed PERT.**

This problem needs to be urgently addressed. Pancreatic Cancer UK has launched a campaign, **Transform Lives: Prescribe**, to do just that. We are working in partnership with the clinical community to improve PERT prescription rates, whilst developing resources and training to support the healthcare community in understanding and prescribing PERT.

But we can't do this alone. To truly solve this problem, there must be a system-wide approach, addressing the issue through three key steps:

1. NHS England should **introduce a national target** for the prescription of PERT to people with pancreatic cancer, aligned with NICE Quality Statement Four. This statement highlights that '*Adults with unresectable pancreatic cancer are prescribed enteric-coated pancreatin*'. NHS England should set a top-down national focus and prioritisation on PERT use within pancreatic cancer care, by:

- **Establishing** a baseline for PERT prescription in England, through auditing and publishing more data on PERT prescription. Pancreatic Cancer UK will collaborate

with Public Health England (PHE) to publish a baseline on PERT prescriptions for people with pancreatic cancer. However, moving forward, NHS England should publish this data annually, to track progress and compliance with the NICE guidelines.

- **Include a target or quality indicator** as part of the pancreas service specification for specialist centres. Cancer Alliances should highlight the NICE guidance and share and promote Pancreatic Cancer UK PERT tools and resources, with a specific focus on channels, networks and outreach within the non-specialist care setting.
- **Prioritising** PERT as a national pancreatic cancer priority for Cancer Alliances and encourage Cancer Alliances to promote Pancreatic Cancer UK training and resources to drive up prescription rates.

2. Cancer Alliances should highlight the NICE guidance and share and promote Pancreatic Cancer UK PERT tools and resources, with a specific focus on channels, networks and outreach within the non-specialist care setting.

3. Healthcare professionals should **prescribe PERT to people with pancreatic cancer as standard**, at the point of diagnosis.

Ultimately, there is no good reason why so many people are missing out on a life-changing treatment such as PERT. Everyone with pancreatic cancer should have the opportunity to live the time they have left with the greatest possible comfort and dignity.

We would appreciate a meeting with you to discuss how we can ensure all people with pancreatic cancer get access to the best possible treatment. Please contact Emily Waller, on emily.waller@pancreaticcancer.org.uk, who will be happy to make the suitable arrangements.

Yours sincerely,

Pancreatic Cancer UK and our undersigned supporters