Pancreatic Cancer UK

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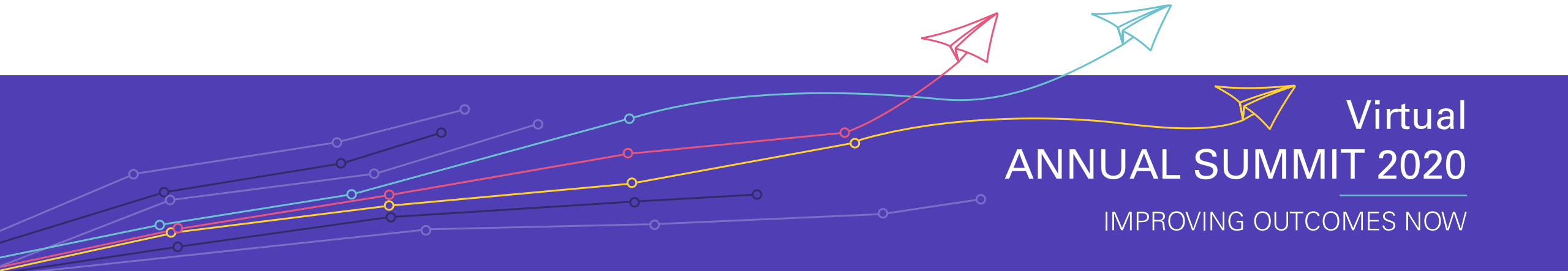
Variation in Access to Optimal Nutritional Care

09.05 – 09.15 | Tuesday 22nd September 2020 | Zoom Webinar

Anna Jewell - Director of Support, Research & Influencing



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Variation in survival

- Despite poor outcomes globally, the UK lags behind the rest of the world, ranking **29th out of 33 countries** for five-year survival.
- One-year survival for pancreatic cancer ranges from **21% to 29%** and five-year survival ranges from **4.8% to 10.6%** across Cancer Alliances
- Variation in treatment and care exists between between young and old, between inoperable and operable and between specialist centres and secondary care

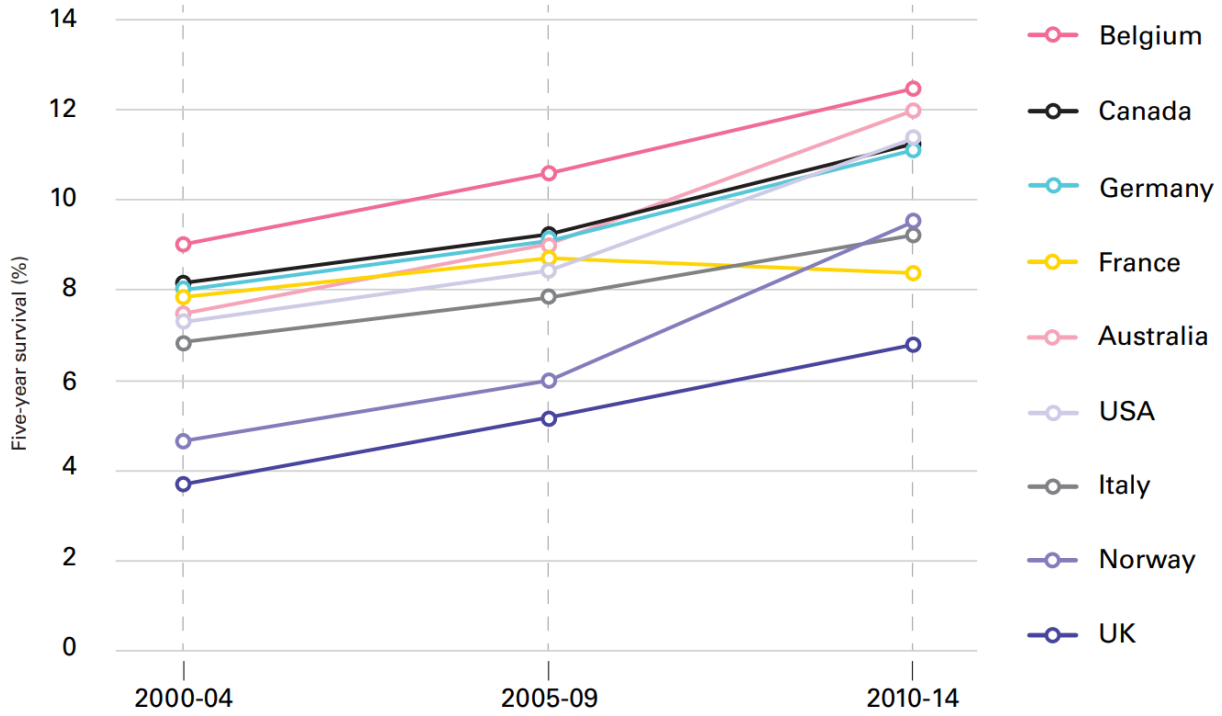

Figure 1: Five-year survival trend for pancreatic cancer between 2000-2004 and 2010-2014. Data adapted after CONCORD-3.

Variation in incidence and mortality

- There is variation in incidence and mortality across CCGs in England.
- There is expected normal random variation in incidence between CCGs with most falling within the control limits, although some CCGs fall outside.
- It is important to start to understand the factors underlying this unexpected variation in mortality and incidence.

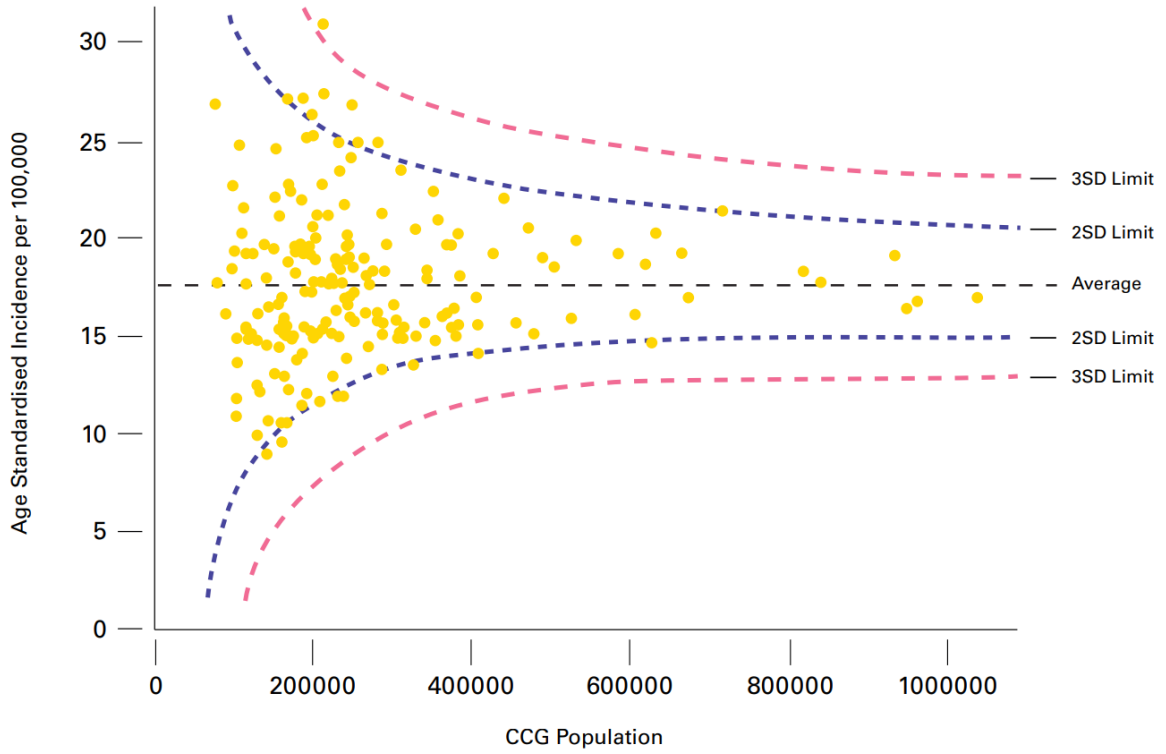

Figure 2: Funnel plot showing the variation in age standardised incidence per 100,000 across the Clinical Commissioning Groups in England (2017). CCGs that lie outside the inner dashed lines (2SD) have unexpected variation and may have real differences in incidence and not random variation. CCGs that lie outside the outer dashed lines (3SD) are more likely to have significant variation in incidence.

Variation in stage

- Variation exists in the stage profile across CCGs, with the proportion of pancreatic cancer cases diagnosed at an early stage ranging from 2.4% to 46.7% across CCGs

- 20.9% of pancreatic cancer cases across England in 2017 had no reported stage and this can be as high as 63% across CCGs.

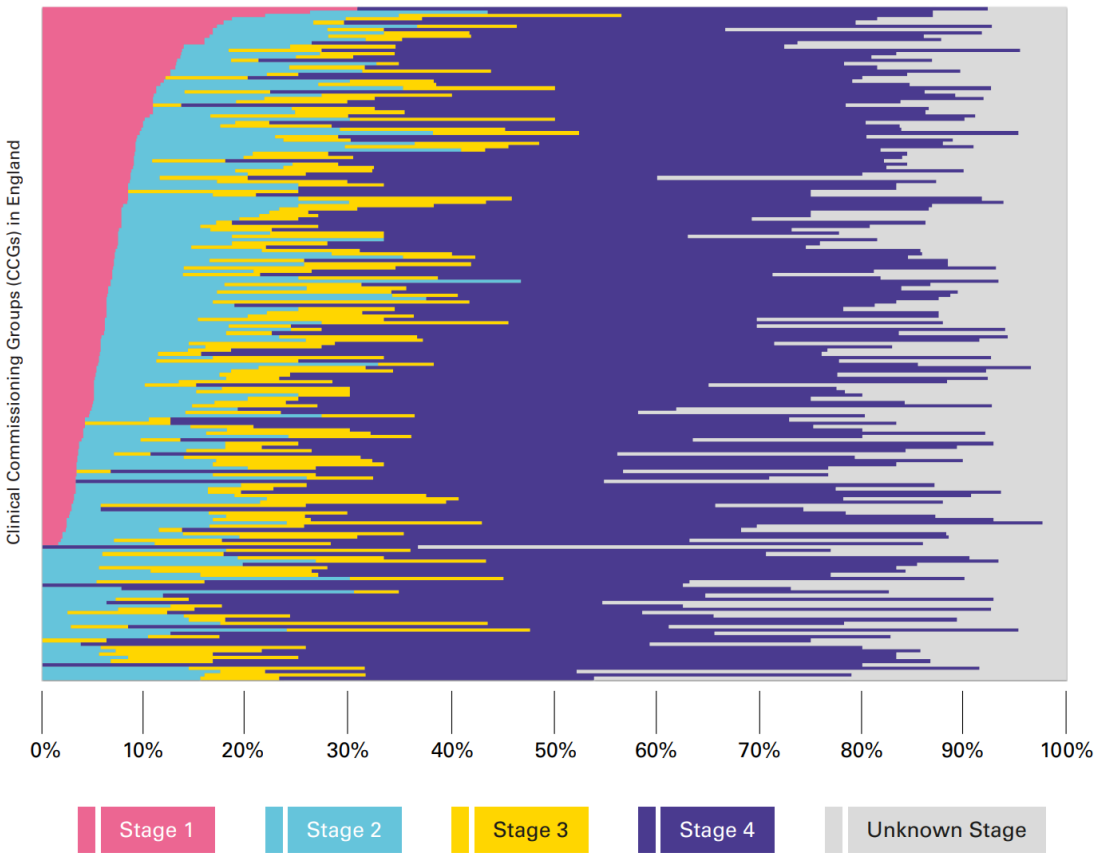

Figure 5: Graph representing the stage profile for pancreatic cancer across all CCGs (2017)[20]

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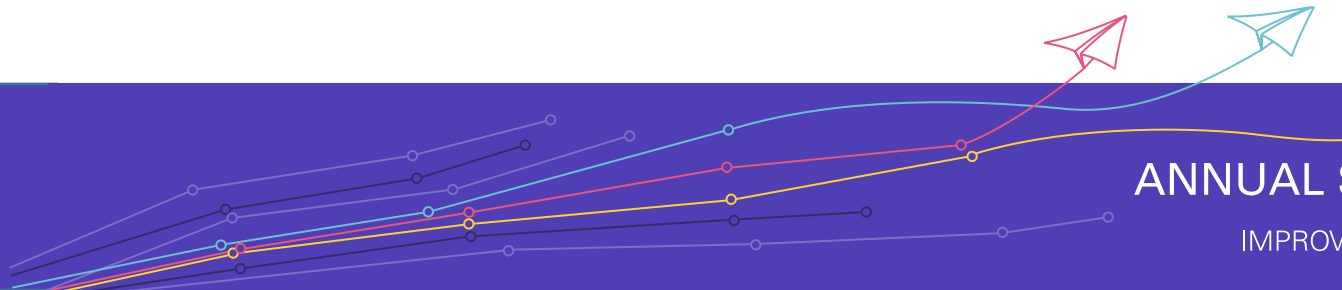
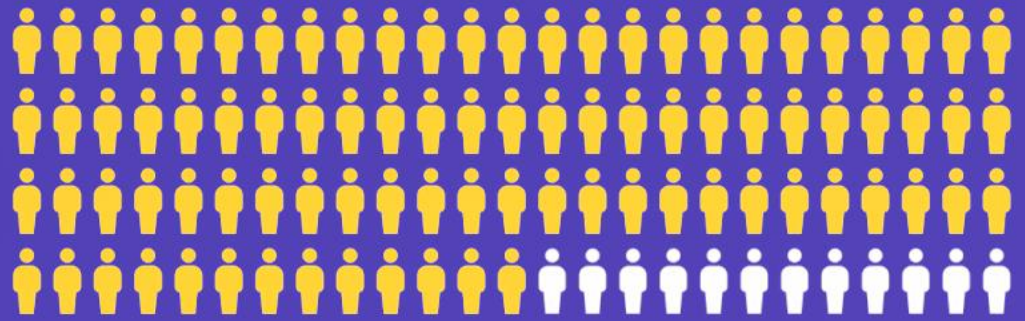
Variation in Access to Optimal Nutritional Care





87%

of people reported that they have one or more supportive care needs

49%

reported one or more moderate or high unmet needs

Unmet nutritional and supportive care needs

- **Pancreatic Cancer UK commissioned PICKER/Oxford Brookes University to quantify the unmet care needs for pancreatic cancer patients**
  - 87% of people reported one or more supportive care needs, with 49% reporting one or more moderate to high unmet needs
  - Digestive problems were the most common supportive care needs (68%)
  - The level of unmet nutritional need was greater in the inoperable group

"I continue to have huge problems with sickness, nausea and diarrhoea. The diarrhoea is sometimes uncontrollable [...] I am exhausted most of the time. I feel isolated; have had to give up full time work and my life now revolves around accessibility to toilets."

"I was not given enough information on discharge from hospital and had to phone the PCUK helpline who sent me a diet sheet. I also found out more from the Whipples warriors Facebook group."

"It wasn't explained to me how to take the enzymes and I had been taking them incorrectly for some time."

"The extended delay meant my weight, muscle and nutritional status and general health deteriorated much more than it should have done."

Variation in access to optimal nutritional care

Pancreatic Cancer UK commissioned PICKER/Oxford Brookes survey found that many pancreatic cancer patients do not receive optimal nutritional care

- 33% of participants prescribed PERT felt they had received insufficient information about PERT
- 20% had not been offered a dietician appointment

Variation in access to Pancreatic Enzyme Replacement Therapy (PERT)

- Pancreatic Exocrine Insufficiency (PEI) is a common supportive care need for pancreatic cancer.
- PERT not only increases quality of life through managing digestive symptoms and reducing weight loss, it can also **increase tolerance to treatment** and **significantly extend the life** of pancreatic cancer patients by **3.8 months.**
- NICE guidelines recommend PERT for all pancreatic cancer patients (both operable and inoperable pancreatic cancer)
- However, **only 54.5%** of pancreatic cancer patients prescribed PERT [RICOCHET, Unpublished Manuscript]

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"There appears little knowledge within GP practices and their support nursing staff of the usage and dosage of Creon [PERT Brand Name]. My dietician had to write to my GP in order for me to obtain the increased amount of Creon. This lack of knowledge led to many weeks of inability to tolerate food."

Variation between operable and inoperable

- The level of unmet supportive care need is greater in inoperable patients than operable
- 29% of inoperable patients reported unmet need for digestive problems
- Inoperable patients are less likely than operable patients to have been offered a dietician appointment (62% vs 77%)
- Inoperable patients are less likely to receive PERT than operable patients (45.3% vs 77.9%). **[RICOCHET, unpublished]**
- A key difference in management of operable and inoperable patients is surgery is centralised to specialist centres, while chemotherapy and palliative care is often delivered in wider local care and often by non-HPB specialists.
- Variation in care seen between patients managed in specialist centres/tertiary care compared to those managed in secondary care - patients more likely to receive PERT in specialist/ tertiary care centres. **[RICOCHET, Unpublished Manuscript]**

Why are people not prescribed PERT?

Currently we know that PERT significantly increases quality of life, symptom burden and survival. **But only 50% of patients will receive PERT.** However, we don't know why people with pancreatic cancer are not prescribed PERT.

Our current hypotheses around low prescription rates include:

A lack of expertise on best supportive care/nutritional care among some healthcare professionals

- Training need - poor awareness of PERT and the benefits
- A belief that PERT is only beneficial if the patient is operable
- Lack of clarity over which healthcare professionals hold the responsibility to prescribe PERT.
- Workforce issues, with not all nurses and dieticians able to prescribe.
- Training need – may be more expertise within specialist/tertiary centre Multidisciplinary Teams compared to secondary care/non-specialist centres

Unanswered questions...

- What are the principal drivers in variation in access to nutritional care and PERT?
- What are the barriers in access to PERT?
- What are potential solutions & tangible changes that can improve access to PERT?

We will be doing a **webinar poll** later in the session looking at these questions. It would be great if you can start thinking about any barriers or solutions...

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Coming up...

- As part of the Virtual Annual Summit 2020 today, we will be exploring innovative practice that aims to improve access to optimal nutritional care and **Pancreatic Enzyme Replacement Therapy (PERT)**

- Through working with the clinical community to share and highlight best practice we can start to reduce unjustified variation in access to PERT and build consensus on optimal nutritional treatment and care.

- We will hear about:
  - The Latest in Nutritional Care **(Oonagh Griffin)**
  - The Impact of a Dietitian Supplementary Prescriber in the Outpatient Oncology Setting **(Andrea Davis)**
  - Improving Access to PERT: Empowering the Patient Through Technology **(Keith Roberts)**
  - Improving Access to Specialist Dietitians: The Manchester Experience **(Neil Bibby)**

Next steps…

Qualitative Research Study:

PCUK have commissioned SAVANTA/COMRES to do a series of interviews with 18 healthcare professionals (including GPs, dieticians, nurses, gastroenterologists, surgeons and oncologists), where we will explore the existing barriers to prescribing PERT and identify potential solutions.

PERT Workshop:

- We are planning two PERT focused workshops, **one for patients and one for healthcare professionals.** The purpose will be to develop realistic solutions to improve PERT prescription rates and build consensus on one low effort, high impact action to improve access to PERT

  - Supporters Date: 3rd November
  - Health Professional Date: 10th November