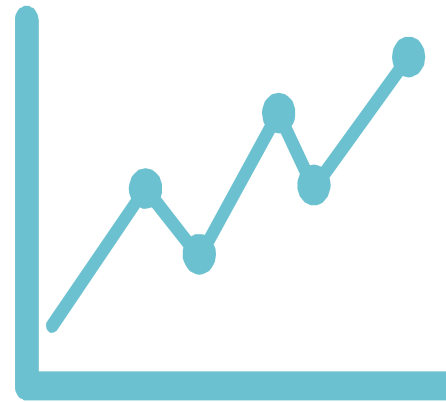
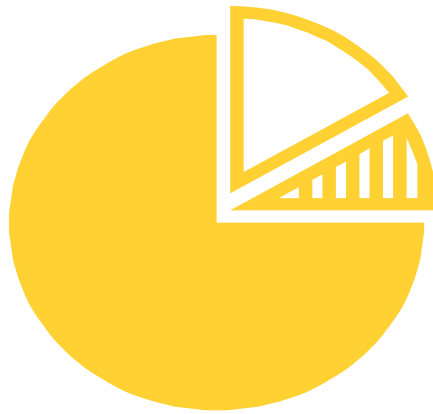
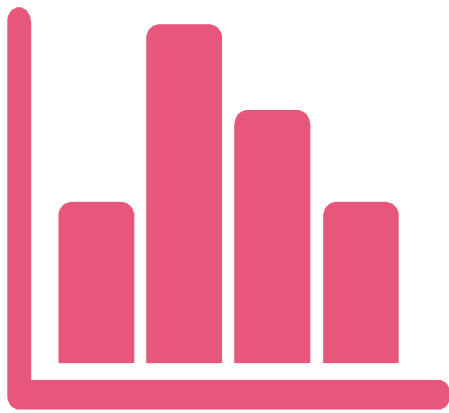


The experiences
and needs of
people affected by
pancreatic cancer

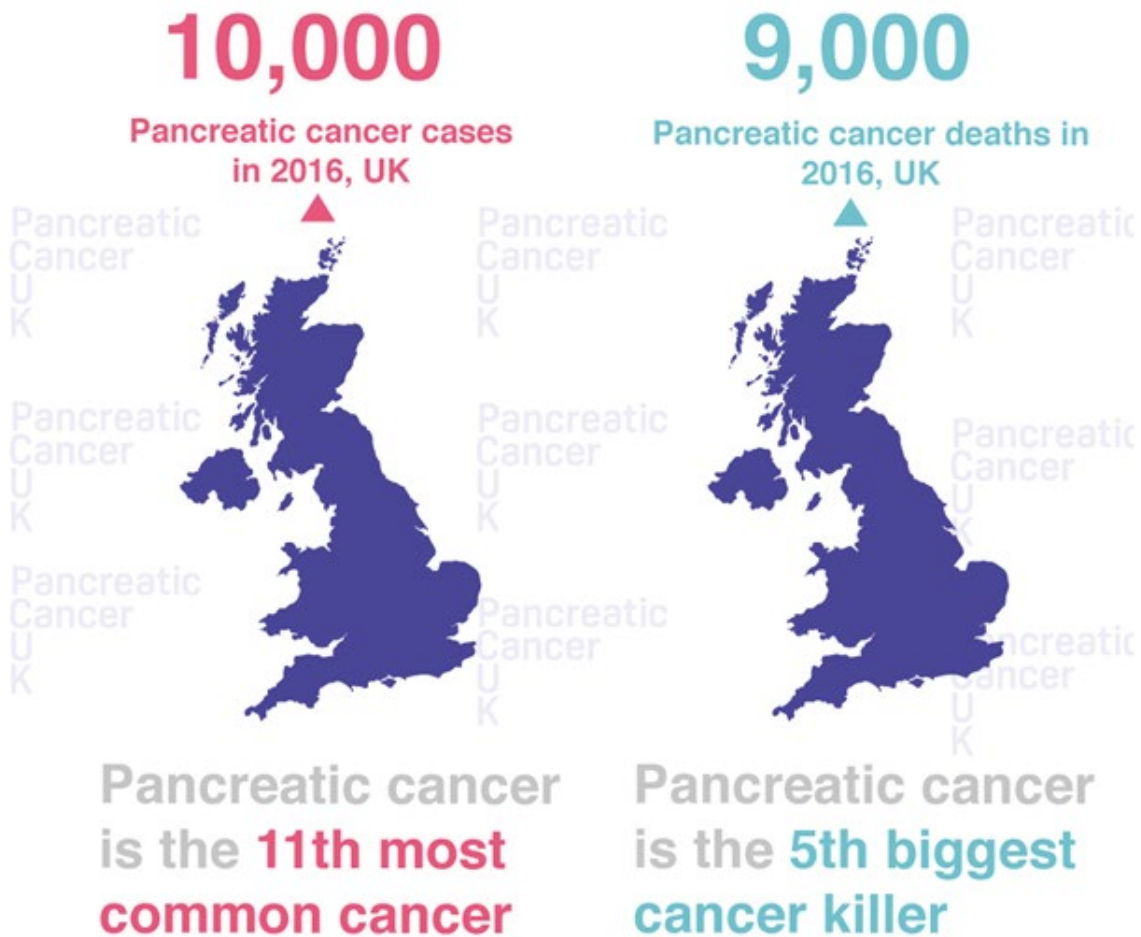
Sarah Bell – Head of Services

Pancreatic cancer – the statistics

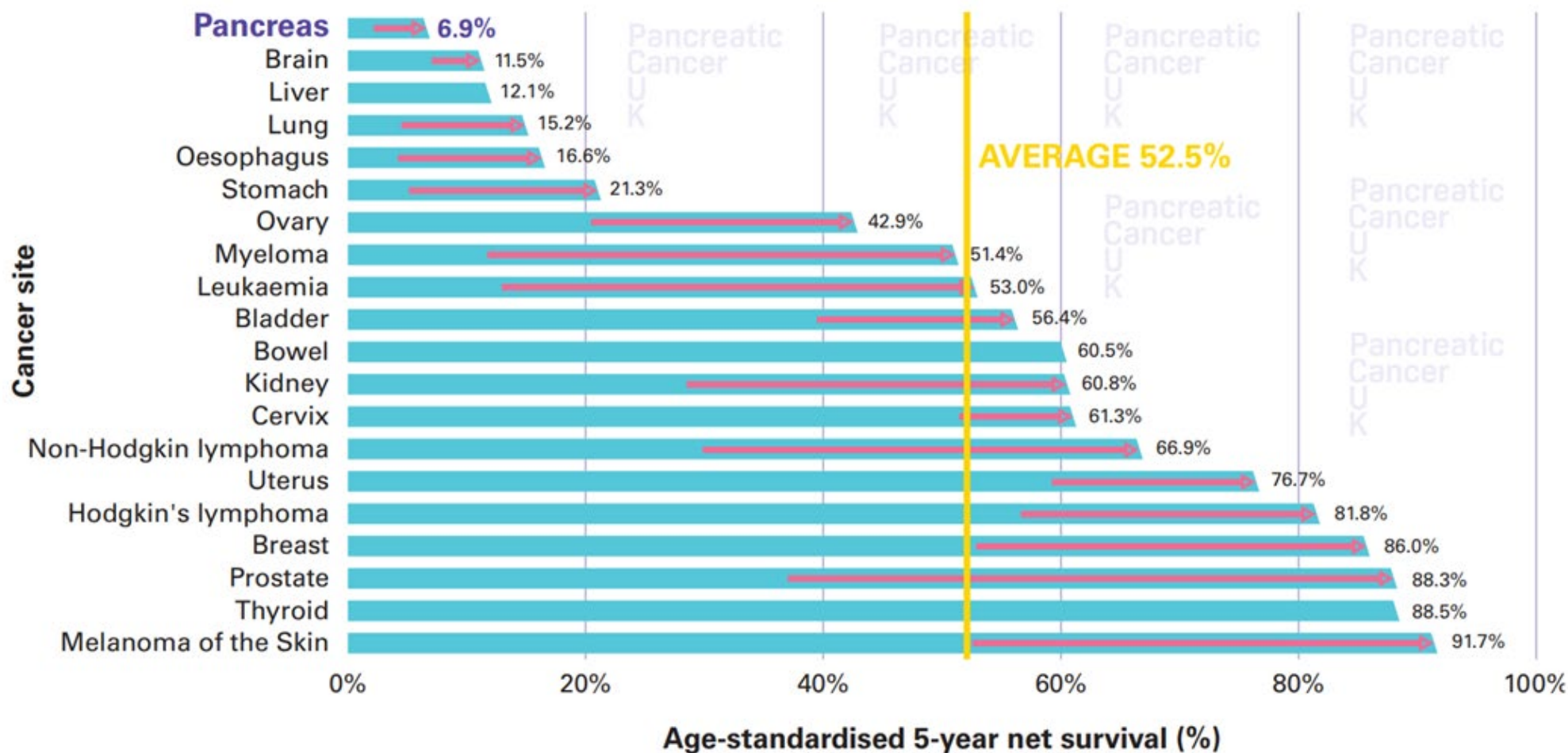


Pancreatic Cancer UK

Deadliest common cancer



Five-year survival in the last 45 years



Low survival rates

Tough to survive

1 in 4 people with pancreatic cancer
will die within a month

3 in 4 people with pancreatic cancer
will die within a year

7%
Five-year survival

24%
One-year survival



Pancreatic cancer has the **lowest**
survival of all common cancers

Early diagnosis – essential to increase survival

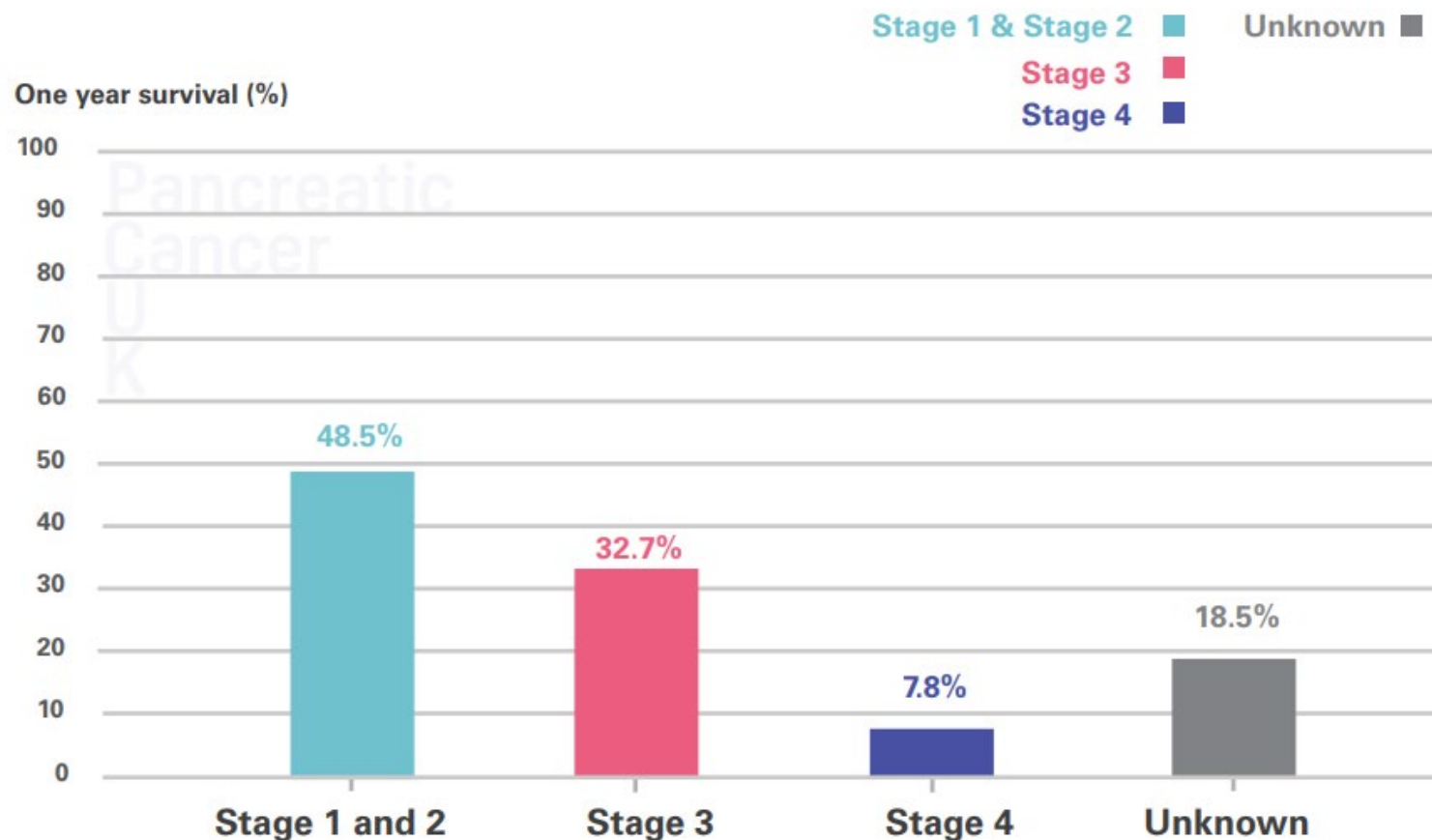


Figure 1: One year survival for people with exocrine pancreatic cancer diagnosed at each stage

Pancreatic cancer symptoms

- Vague and non specific symptoms
- Symptoms often don't present until a late stage
- No simple diagnostic test

**Abdominal
(tummy)
pain which
can spread
to the back**



**Unexplained
weight loss
and loss
of appetite**



**Jaundice
(yellow skin
or eyes)**



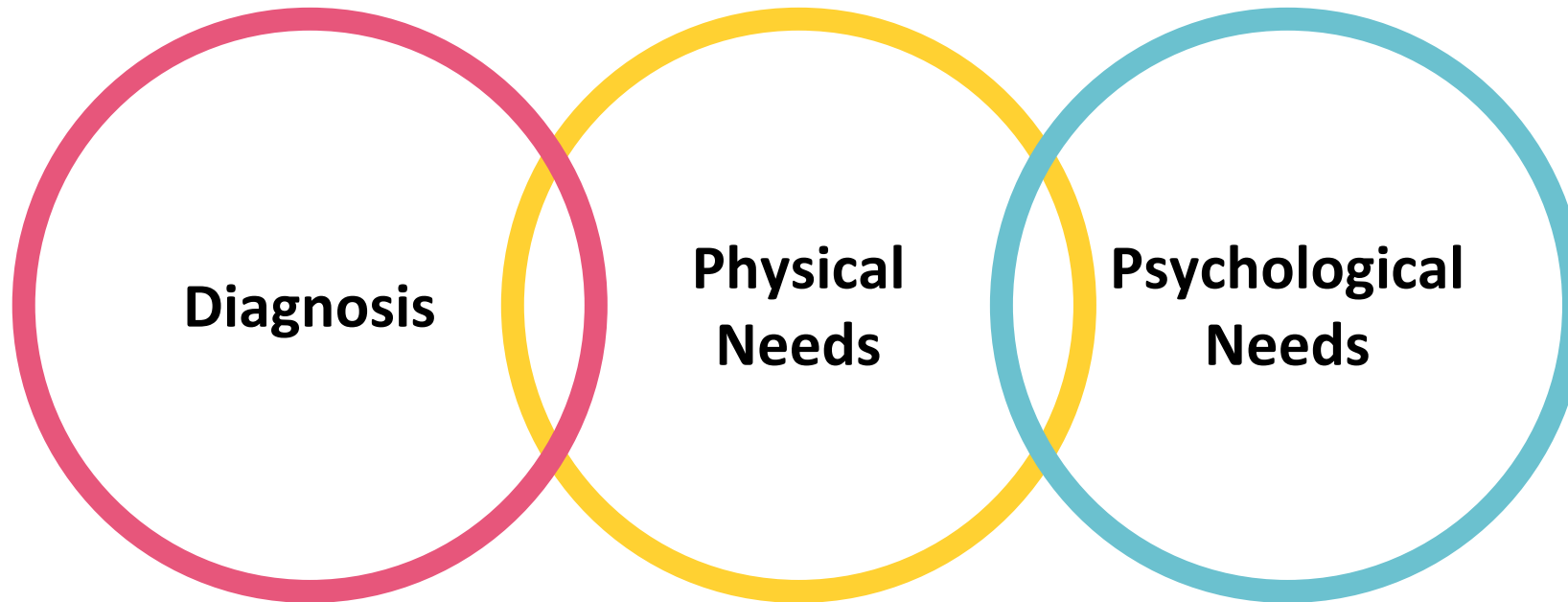
**Oily
floating
poo**



Indigestion



Pancreatic cancer – experiences and needs



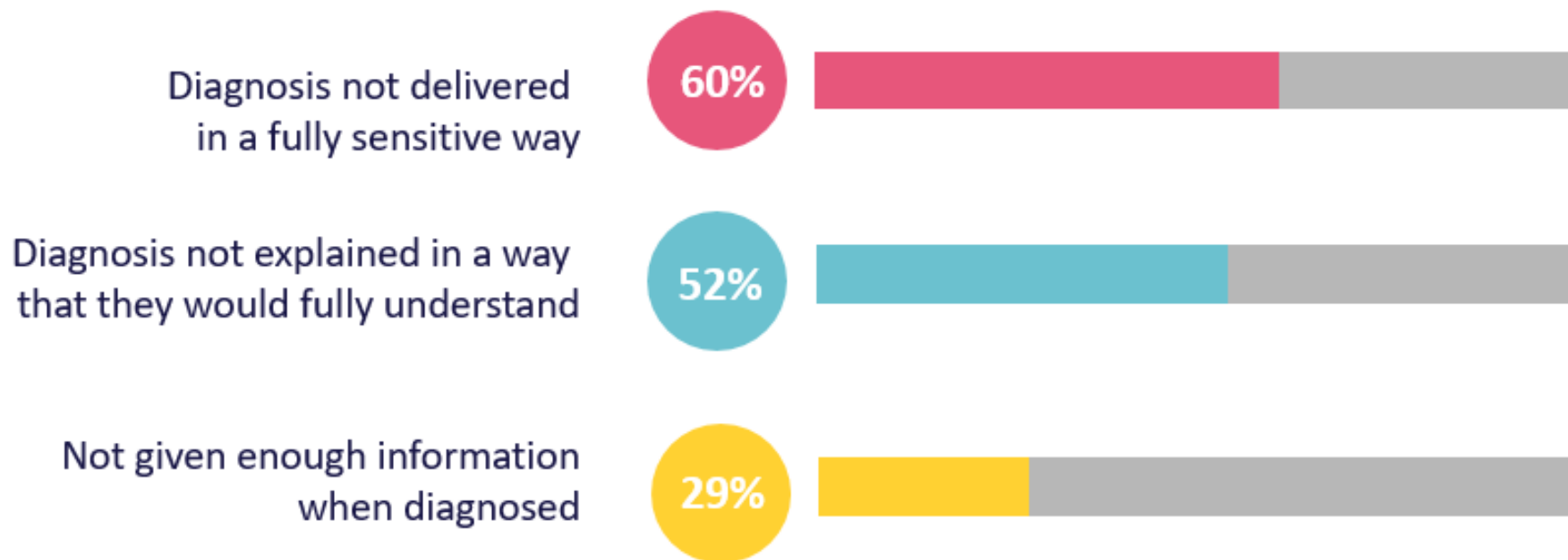
Devastated, frightened,
emotional, unsure, angry. I
feel depressed, scared,
lonely, isolated

I knew something was wrong
but I would never have guessed
it would be this. I don't know
what the pancreas does

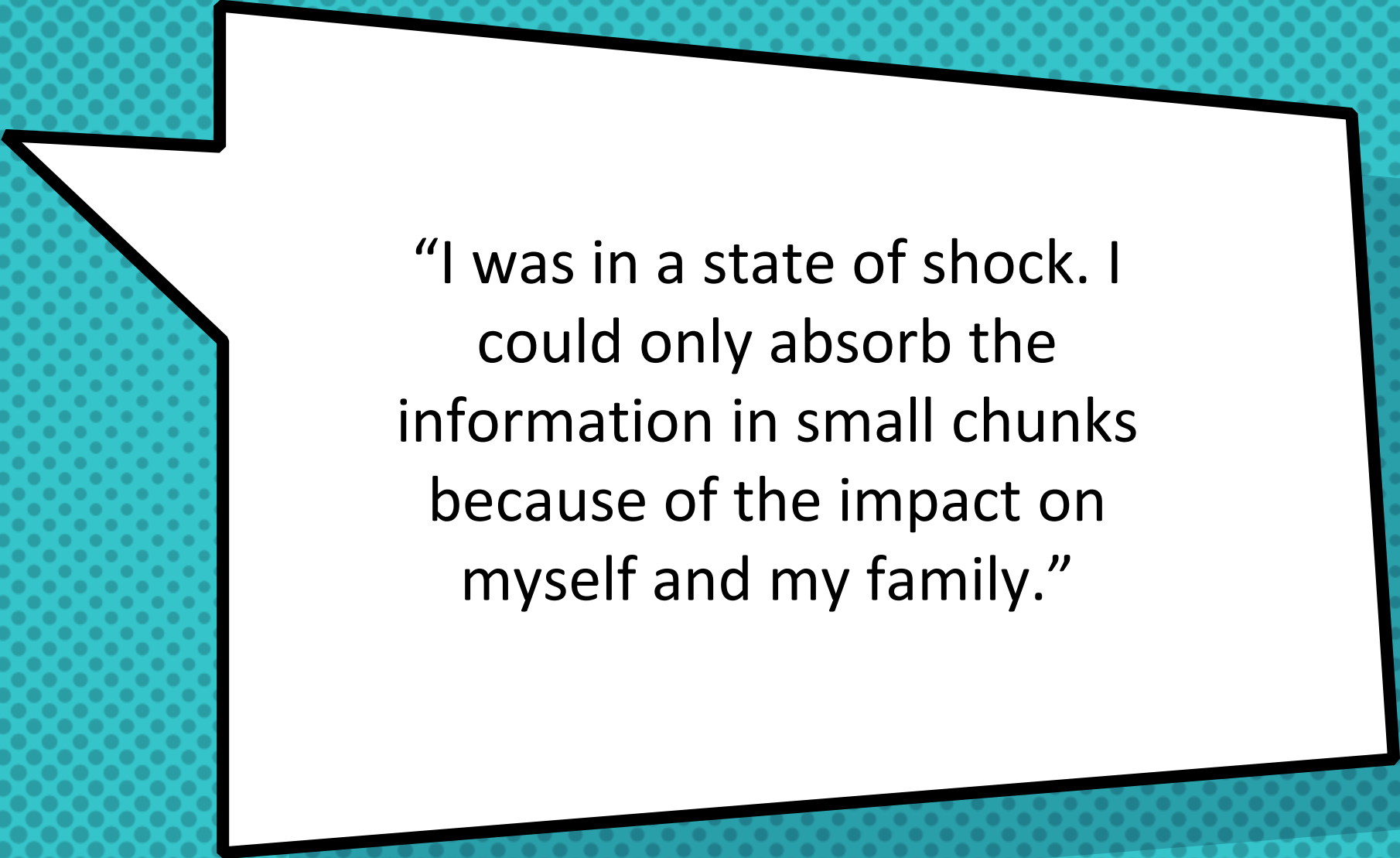
What caused me
to get pancreatic
cancer?

Diagnosis

Experience when diagnosed



Inoperable patients reported poorer experiences than operable



“I was in a state of shock. I
could only absorb the
information in small chunks
because of the impact on
myself and my family.”

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

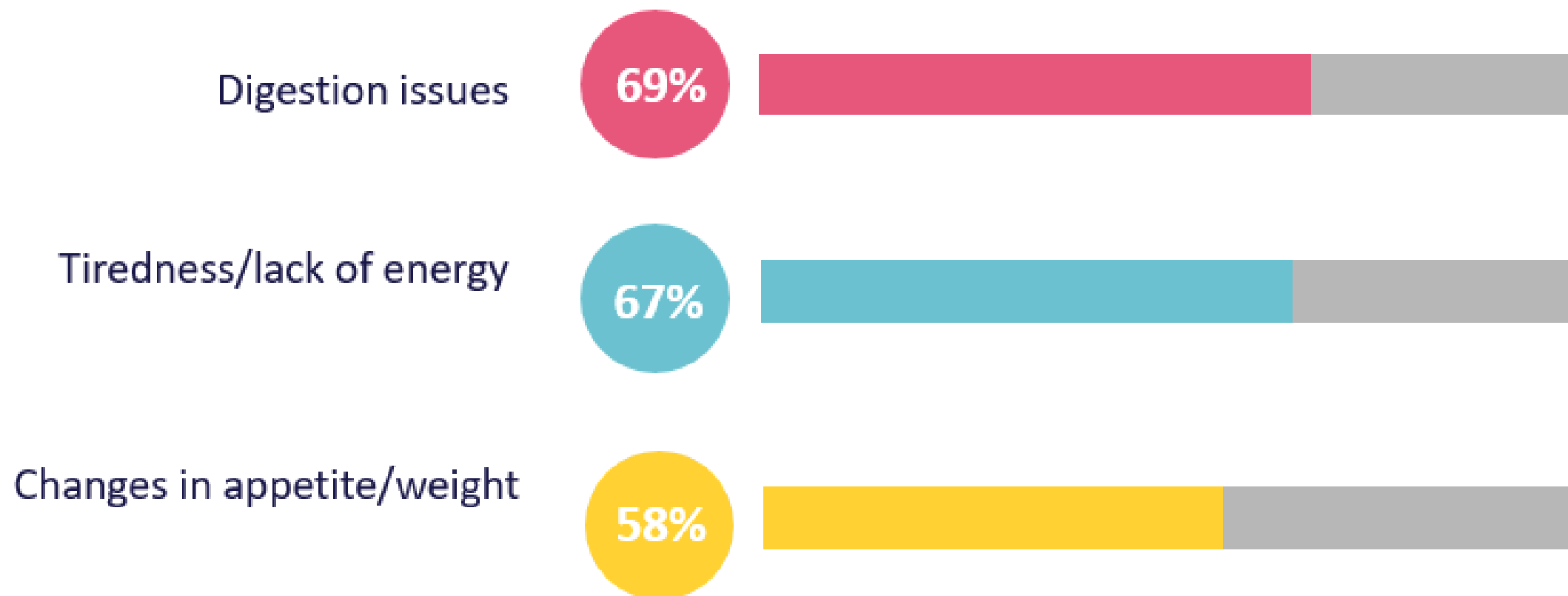
I continue to have huge problems with sickness, nausea and diarrhoea. I am exhausted most of the time. I feel isolated; have had to give up full time work and my life now revolves around accessibility to toilets.

I am frustrated about how much I am struggling with symptoms

I have constant ongoing issues like fatigue

Physical
Needs

Physical care needs



- Symptoms can be a major source of distress – nausea and vomiting, indigestion and diarrhoea and taste disturbance
- Feelings of not being able to control their illness – fielding endless questions about diet and weight

(Wong et al. Using photography to explore psychological distress in patients with pancreatic cancer and their caregivers, 2019)

- Restriction this has on activity and not being able to do things used to

(Beesley et al. A tsunami of unmet needs: Pancreatic cancer patients' supportive care needs, 2016)

Dietary support

Prescribed PERT but not
given enough information

33%

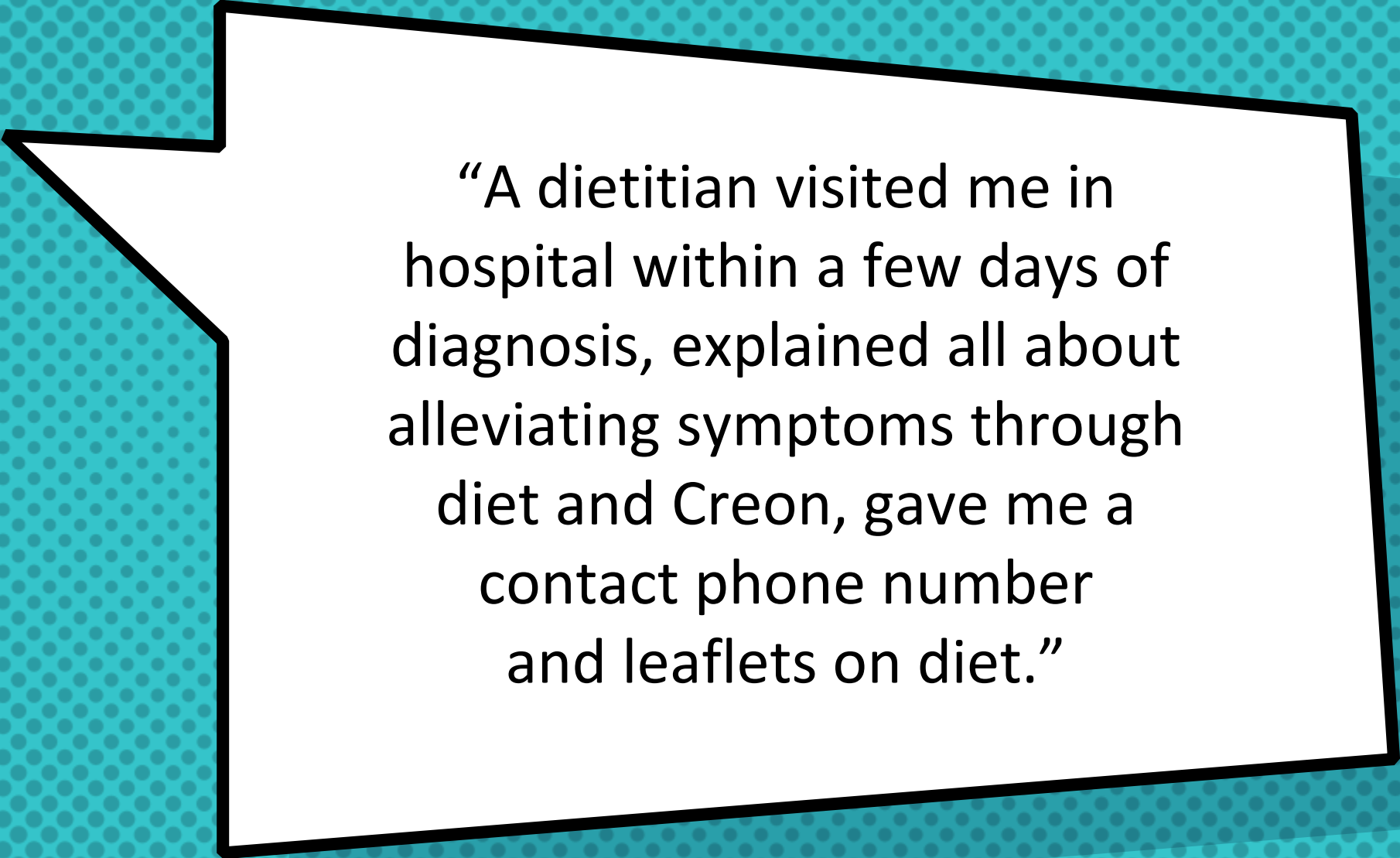


Not offered a dietitian
appointment

20%



Inoperable patients less likely than operable patients to have seen a dietitian



“A dietitian visited me in hospital within a few days of diagnosis, explained all about alleviating symptoms through diet and Creon, gave me a contact phone number and leaflets on diet.”

We're not talking to our wider family about this. I never talk about it

It would be good to receive psychological support for guilt as a survivor of pancreatic cancer

I feel shame and guilt that I didn't realise it was pancreatic cancer

I'm still waiting for treatment

Psychological
Needs



87%

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

Uncertainty about the future

68%



Fears about cancer spreading

67%





49%

reported one or more
moderate or high
unmet needs

22%
needed help
with anxiety

25%
needed help with
concerns about
the worries of
those close to
them

21%
needed help
with feelings
of sadness

- Significant association between patient and carer anxiety levels – carers reporting more severe anxiety than patients
- Higher proportion of patients reported having positive emotions like hope when diagnosed. Caregivers more frequently than patients described feeling heartbroken or devastated

(Janda et al, Anxiety, depression and quality of life in people with pancreatic cancer and their carers, 2017)

- Caregivers recognise the importance and need for self-care, yet actively choose not to do so due to feelings of guilt and selfishness for taking time away from patient

(Wong et al. Using photography to explore psychological distress in patients with pancreatic cancer and their caregivers, 2019)

Managing physical and psychological needs

- NICE acknowledge role that physical symptoms can play in psychological wellbeing, advising assessment of:
 - fatigue, pain, gastro symptoms, nutrition, anxiety and depression
- NICE recommends that people with pancreatic cancer and their families should be provided with information and support to help manage psychological impact:
 - Available on an ongoing basis
 - Relevant to the stage of the person's condition
 - Tailored to the person's needs

<https://www.nice.org.uk/guidance/ng85/chapter/Recommendations#psychological-support>

“ It can be a very lonely cancer.
There seems to be a lot of
support for other well-known
cancers. I feel cancer should be
cancer, no matter where it is,
and everyone should
get the same support.”

Pancreatic cancer – addressing the needs



Series of 4 easy read booklets about pancreatic cancer:

1. What pancreatic cancer is and how it's diagnosed
2. Treatment for inoperable cancer
3. Surgery to remove pancreatic cancer
4. Managing symptoms and getting support

- Simple words and pictures to present information
- Designed for people with learning disabilities, but can also be helpful for people who struggle with written information, including those with lower health literacy skills and people who don't speak English as a first language.



Free to order or download from pancreaticcancer.org.uk/publications

We would like to see existing models of best practice on pancreatic cancer packaged up in an optimal pathway

- Best practice models that fully support the NICE Guidelines '*Suspected cancer: recognition and referral*' and '*Pancreatic cancer in adults: diagnosis and management*'
- Focus on improvement in **diagnosis, treatment** and **personalised cancer care**
- We are meeting the national NHS England cancer policy team to promote these models as well as sharing with health professionals
- We would love to hear from you if you're working on something which could feature in an optimal pathway for pancreatic cancer

Funding of up to **£50,000** available for innovative project ideas lasting a **maximum of 12 months**.

Projects should focus on **practical interventions within the clinical or community setting** that can be adopted to ensure that patients with pancreatic cancer get the best treatment and care.

- Diagnostic pathway
- Treatment pathway
- Supportive care pathway

DEADLINE – 27th NOVEMBER, 2019

pancreaticcancer.org.uk/clinicalpioneerawards

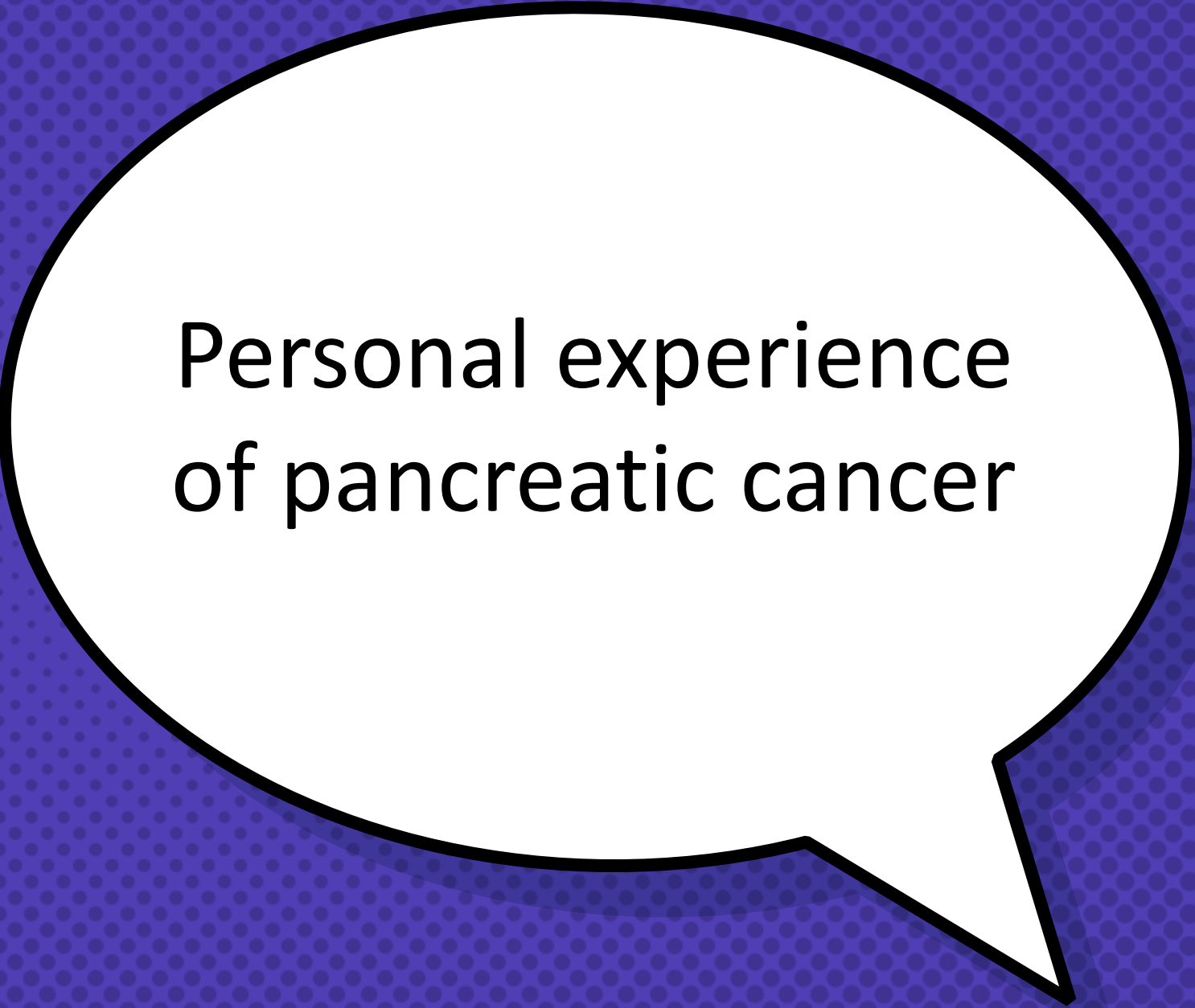
DON'T MISS
THE DEADLINE!

Personalised holistic care
treatment and
psychological support

I was diagnosed in 2 weeks, fast
tracked, scan and everything
happened in one place

Shared decision
making

All symptoms
are managed
well



Personal experience
of pancreatic cancer

Nikki Davies