

#PCUKStudyDay



# Optimising quality of life in pancreatic cancer

10th September 2025

9:00 – 11:00am

Via Zoom Webinar

#PCUKStudyDay



# Welcome and introduction

Nicci Murphy

Clinical Lead and Pancreatic Cancer Specialist Nurse, Pancreatic Cancer UK

# Agenda

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**09.00 – 09.05**     **Welcome** – Nicci Murphy, Clinical Lead and Pancreatic Cancer Specialist Nurse, Pancreatic Cancer UK

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**09.05 – 09.20**     **Introducing quality of life and key themes** – Lynne McCallum, Pancreatic Cancer Specialist Nurse, Pancreatic Cancer UK

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**09.20 – 10.30**     **Case study and panel session** – chaired by Nicci Murphy, Clinical Lead Specialist Nurse, Pancreatic Cancer UK

- Dr Robin Muir
- Neil Bibby
- Melanie Allen
- Dr Ruth Corbally
- Gemma Kindness

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**10.30 – 10.50**     **Q&A** – with our panellists, chaired by Nicci Murphy

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**10.50 – 11.00**     **Close**

# Quality of Life in Pancreatic Cancer: A Refresher

- Defining Quality of Life (QoL)
- Core Pillars of QoL
- QoL Considerations in PDAC
- Approaches to Assessing QoL

**“person’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.”**



# What Quality of Life Means for Patients

- Active involvement in their own care
- Reduced anxiety and improved mood
- Better response to treatment
- Faster and more effective recovery
- Ability to focus on what matters most
- Greater sense of control and independence
- Enhanced capacity to achieve personal goals

# Why Quality of Life Matters in PDAC

- Cancer impacts QoL across **physical, emotional, and social** domains
- **Challenges are often more pronounced** in pancreatic cancer
- PDAC typically **presents late** with **high symptom burden**
- **Low mood** is more prevalent in PDAC than other cancers
- **Severe symptoms** often persist to end of life, contributing to poor QoL

[Supportive care needs of people with pancreatic cancer: a literature review](#)

[The importance of quality-of-life management in patients with advanced pancreatic ductal adenocarcinoma - ScienceDirect](#)<sup>7</sup>

# Guidelines in PDAC

**NICE** National Institute for  
Health and Care Excellence

## Pancreatic cancer in adults: diagnosis and management

NICE guideline | NG85 | Published: 07 February 2018

- People should have access to **psychological support throughout their care pathway**
- Support should be tailored to individual needs
- **There should be assessment of the psychological effects of:**
  - Fatigue
  - Pain
  - GI symptoms – including nutrition
  - Nutrition
  - Anxiety
  - Depression

[Recommendations | Pancreatic cancer in adults: diagnosis and management | Guidance | NICE](#)



**Gentle exercise**



**Emotional well-being**



**Diet and digestion**



**Treat any symptoms**

# The Value of Measuring QoL in PDAC

- A key component of **personalised, holistic care**
- Helps us understand the impact of PDAC on everyone's life
- Supports **timely, person-centred palliative and supportive care**
- Offers insight into the lived experience of illness over time

# The challenges

- Defining and **measuring quality of life is complex**
- **Multiple assessment tools exist** – selecting the most appropriate can be challenging
- Time limitations in clinical practice
- Constraints of the clinic environment
- Resource and staff capacity considerations
- Determining responsibility for conducting assessments

# Using the right tool for the job!

## Quality of life measurement tools need to be:

- Easy to complete
- Not too long
- Can be used and repeated at relevant times
- Meaningful to the patient
- Actionable
- Not only focussed on treatment and/or symptom metrics
- Can be used to develop care plans based on the priorities of the individual
- It enables the individual to make informed decisions

## What tools do you use in your practice?

# What tools did I use in practice?


- EORTC QLQ-C30
- EORTC QLQ - PAN26
- Holistic Needs Assessment (HNA)
- Eastern Cooperative Oncology Group Performance Status (ECOG PS)

# Examples

1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any selfcare; totally confined to bed or chair
5	Dead


## ECOG performance status

The ECOG Performance Status Scale was developed by the Eastern Cooperative Oncology Group (ECOG), now the ECOG-ACRIN Cancer Research Group, and published in 1982. To learn more, visit [ecog-acrin.org/scale](https://ecog-acrin.org/scale).



**EORTC QLQ-C30 (version 3)**

We are interested in some number that best applies remain strictly confidential



**EORTC QLQ - PAN26**

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

## Specimen-PAN26

## Specimen-QLQ-C30.pdf

## Macmillan HNA

### Concerns Checklist – identifying your concerns

Patient's name or label

**Key worker:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Contact number:** \_\_\_\_\_

This self-assessment is optional; however, it will help us understand the concerns and feelings you have. It will also help us identify any information and support you may need.

If any of the problems listed have caused you concern recently and you wish to discuss them with a key worker, **please score the concern from 1 to 10, with 10 being the highest**. Leave the box blank if it doesn't apply to you, or you don't want to discuss it now.

**Key worker to complete**

☐ Copy given to patient.

☐ Copy to be sent to GP

**Physical concerns**

- ☐ Breathing difficulties
- ☐ Passing urine
- ☐ Constipation
- ☐ Diarrhoea
- ☐ Eating, appetite or taste
- ☐ Indigestion
- ☐ Swallowing
- ☐ Cough
- ☐ Sore or dry mouth or ulcers
- ☐ Nausea or vomiting
- ☐ Tired, exhausted or fatigued
- ☐ Swelling
- ☐ High temperature or fever
- ☐ Moving around (walking)
- ☐ Tingling in hands or feet
- ☐ Pain or discomfort
- ☐ Hot flushes or sweating
- ☐ Dry, itchy, or sore skin
- ☐ Changes in weight
- ☐ Wound care
- ☐ Memory or concentration
- ☐ Sight or hearing
- ☐ Speech or voice problems
- ☐ My appearance
- ☐ Sleep problems

☐ I have questions about my diagnosis, treatment, or effects.

☐ Sex, intimacy or fertility

**Practical concerns**

- ☐ Other medical conditions
- ☐ Taking care of others.
- ☐ Work or education
- ☐ Money or finance
- ☐ Travel
- ☐ Housing
- ☐ Transport or parking
- ☐ Talking or being understood
- ☐ Laundry or housework
- ☐ Grocery shopping
- ☐ Washing and dressing
- ☐ Preparing meals or drinks
- ☐ Pets
- ☐ Difficulty making plans.
- ☐ Smoking cessation
- ☐ Problems with alcohol or drugs
- ☐ My medication

**Emotional concerns**

- ☐ Uncertainty
- ☐ Loss of interest in activities
- ☐ Unable to express feelings
- ☐ Thinking about the future
- ☐ Regret about the past
- ☐ Anger or frustration

☐ Loneliness or isolation

☐ Sadness or depression

☐ Hopelessness

☐ Guilt

☐ Worry, fear, or anxiety.

☐ Independence

**Family or relationship concerns**

- ☐ Partner
- ☐ Children
- ☐ Other relatives or friends
- ☐ Person who looks after me
- ☐ Person who I look after

**Spiritual concerns**

- ☐ Faith or spirituality
- ☐ Meaning or purpose of life
- ☐ Feeling at odds with my culture, beliefs or values

**Information or support**

- ☐ Exercise and activity
- ☐ Diet and nutrition
- ☐ Complementary therapies
- ☐ Planning for my future priorities
- ☐ Making a will or legal advice
- ☐ Health and wellbeing
- ☐ Patient or care support group
- ☐ Managing my symptoms
- ☐ Sun protection

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MAC15889 ConcernsChecklist 24-EN

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# Final Reflections on Quality of Life

- It is **unique to the individual**
- Consider in every clinical encounter
- **Central to personalised, holistic care**
- Symptom management **reduces distress and enhances QoL**
- Empowers patients and their loved ones
- **Communication is our most valuable tool**
- Requires a coordinated MDT approach

# Case Study 1

Barbara, 67, presented with onset of jaundice. Imaging showed an operable mass on the head of pancreas and referred to surgery.

Barbara lives alone but has good family and friend support locally. Surgery planned for 3 weeks' time.

Recent ERCP for bile duct stent, bilirubin levels decreasing and symptoms improving. No signs of infection, eating and drinking well.

## **ECOG Performance Status – 1**

### **Current issues:**

- Recent unexplained weight loss
- Pale stools.
- Some discomfort to abdomen, worse as day progresses.

# Case Study 2

Sarah, 71, diagnosed with inoperable head of pancreas cancer, with known liver metastases. Has been offered Gemcitabine Abraxane chemotherapy and is due to start in 4 weeks' time.

Lack of social support. Sarah is the main carer for husband with dementia.

## **ECOG Performance Status – 2**

### **Current issues:**

- Emotional distress, fears for the future.
- Anorexia and ongoing weight loss, ++.
- Elevated HbA1c, abdominal pain, insomnia.

# Case Study 3

Bob, 71, found to have metastatic disease within 12 months of Whipple's surgery and adjuvant FOLFIRINOX chemotherapy.

Considers treatment options but has made the decision (with support from family) to focus on quality of life so declines chemotherapy.

Bob's son is getting married in 2 months' time and his focus is being able to attend the wedding.

## **ECOG Performance Status – 2**

### **Current issues:**

- Pain
- Ongoing diarrhoea since surgery
- Reduced mobility
- Chemotherapy induced peripheral neuropathy

# Key takeaway messages

- **Check that any patient with pancreatic cancer is being prescribed PERT.** Don't be afraid to trial higher doses if needed. If your patients need further support with taking PERT, the Pancreatic Cancer UK Support Line is available.
- **Prioritise proactive care and communication,** early interventions and support, rather than waiting for problems to arise.
- **Good care is built upon professionals working across different domains and in a multi-disciplinary manner,** i.e. considering treatment decisions in terms of what the person values.
- **Be aware of patients' additional challenges,** respond to these and consider how we can support patients to be involved in their own care.
- **Find out what services are available** in your area that can offer help and support for your patients and families. **There are often council and charity led resources** that we can tap into in addition to our NHS resources.
- **Don't hesitate to discuss physical activity.** You don't need to be an expert in it - encouraging movement is generally safe and offers significant health benefits. Even small increases in activity can make a meaningful difference