

What do the patients want to know?

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Pancreatic cancer carer

TVCN Upper GI TSSG

NCRI Upper GI CSG and CLG

NCIN Upper GI TSSG

Pancreatic Cancer UK

Cancer 52

Input from David Kirby Oesophageal Patients Association

Gwen Harlow, Oesophageal Patient support, NCRI CLG

Paul Morris pancreatic cancer survivor, NCRI CLG,

Alison Stunt pancreatic cancer survivor

Pancreatic Cancer Awareness Week 16-22 Nov

On Diagnosis

- Don't know what we want to know
- Want to know getting best possible care as fast as possible
- Want to know where centres of excellence are
 - However actually want every centre to have best care and outcomes
 - However may want choice if there are different ways of doing things eg keyhole surgery
 - Want access to trials wherever they are in UK
 - Want access to 2nd or 3rd line treatment wherever in UK

Info needs

- Cases per surgeon/oncologist and survival rates – at least 2/month minimum
- At least 2 surgeons per centre
- Whether research/trials happening
- What resources available eg CNS, palliative care, dieticians, follow up
- Cardiothoracic v UGI surgeon for O-G
- Speed of actions after diagnosis and speed of diagnosis

On reflection

- Don't want to enforce everyone to be the same – stifles innovation and research?
- However want everyone to have highest standards
- What is best practice?
- What is the case mix? Eg co-morbidities etc

Unanswered Questions

- Why does 1 year survival in UK for pancreatic cancer vary from 10.7% in N Trent to over 20% in N , W, SW London and Surrey and Sussex and Europe and SW Australia?
- Why does 1 year and 3 year survival for O-G cancers vary so much between networks?

Unanswered Questions

- Diagnosis
 - Are there delays and what causes them?
 - Broken down by cancer type not just Upper GI
- Outcomes
 - Do we need 6 month survival rates for this group of cancers?
 - Follow-up methods?
- Service provision, quality of life
- Broken down by cancer subtype eg adenocarcinoma, squamous, neuroendocrine