

Pancreatic Cancer Action Patient and Carer Survey 2015

The survey was conducted online using Survey Monkey between 17th August and 16th October 2015

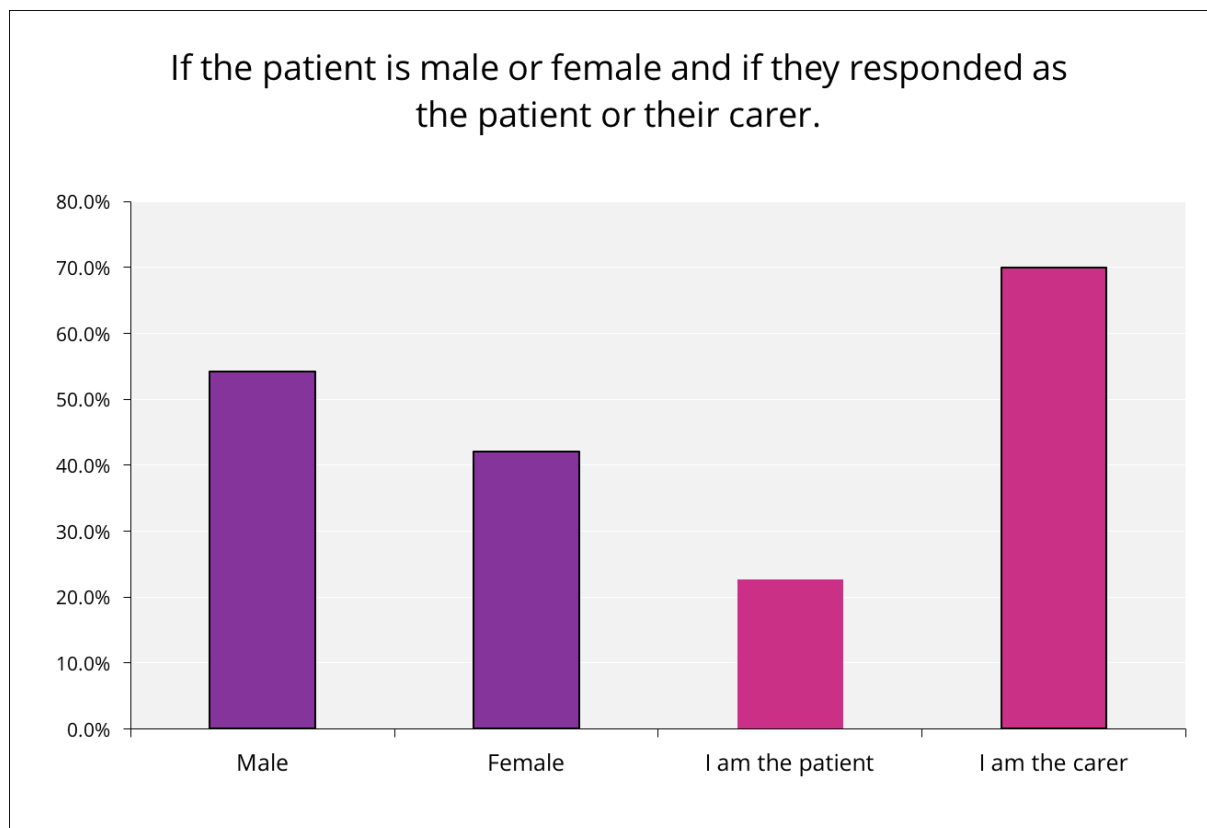
190 respondents made up of:

Men: 56%

Women: 44%

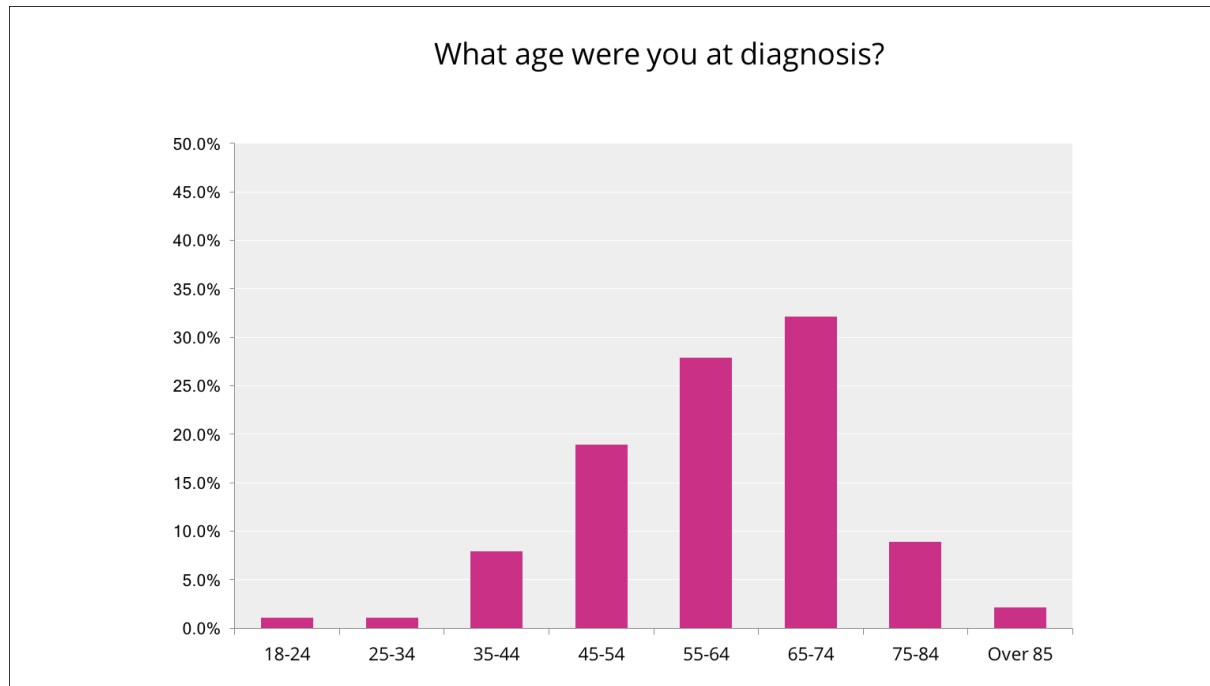
Carers: 75.6%

Patients: 24.4%



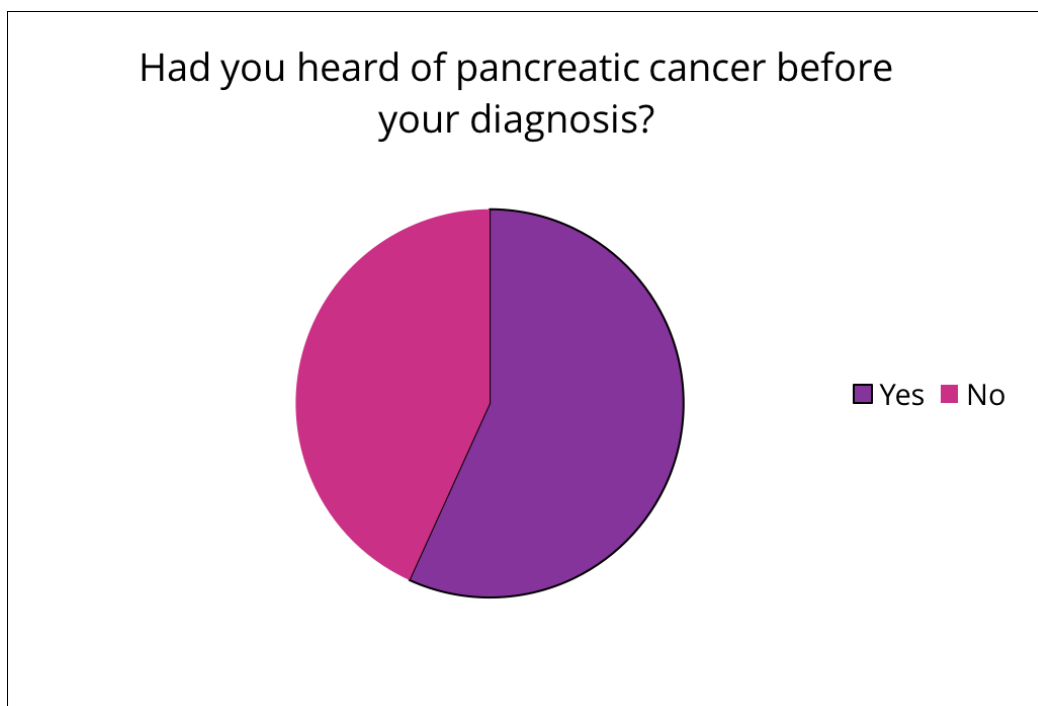
Age at diagnosis:

The largest group of patients were the 65-74 age (32%) however, 57% of patients were aged less than 64 on diagnosis and 29% were aged less than 54. This lower age group may be reflected by the fact that this was an online survey.



Awareness of pancreatic cancer before diagnosis

57% of respondents had heard of pancreatic cancer before their own diagnosis although 43% (nearly half) had not.



Symptoms

Respondents were asked what the first symptom(s) were that prompted them to seek help from a doctor. Respondents were totally unprompted.

Symptom	No. of respondents	% of respondents
Abdominal pain	50	26
Back pain	25	13
Jaundice	22	11
Indigestion	16	8
Weight loss	13	7
Change in bowel habit	11	6
Fatigue	9	5
Nausea/sickness	8	4
Difficulty eating/pain on eating	7	4
Diabetes	5	3
Bloating	5	3
Chest pain	4	2
Itchy skin	4	2
Depression	3	2
Pale, smelly stools	3	2
Pancreatitis	3	2
Total*	194	100

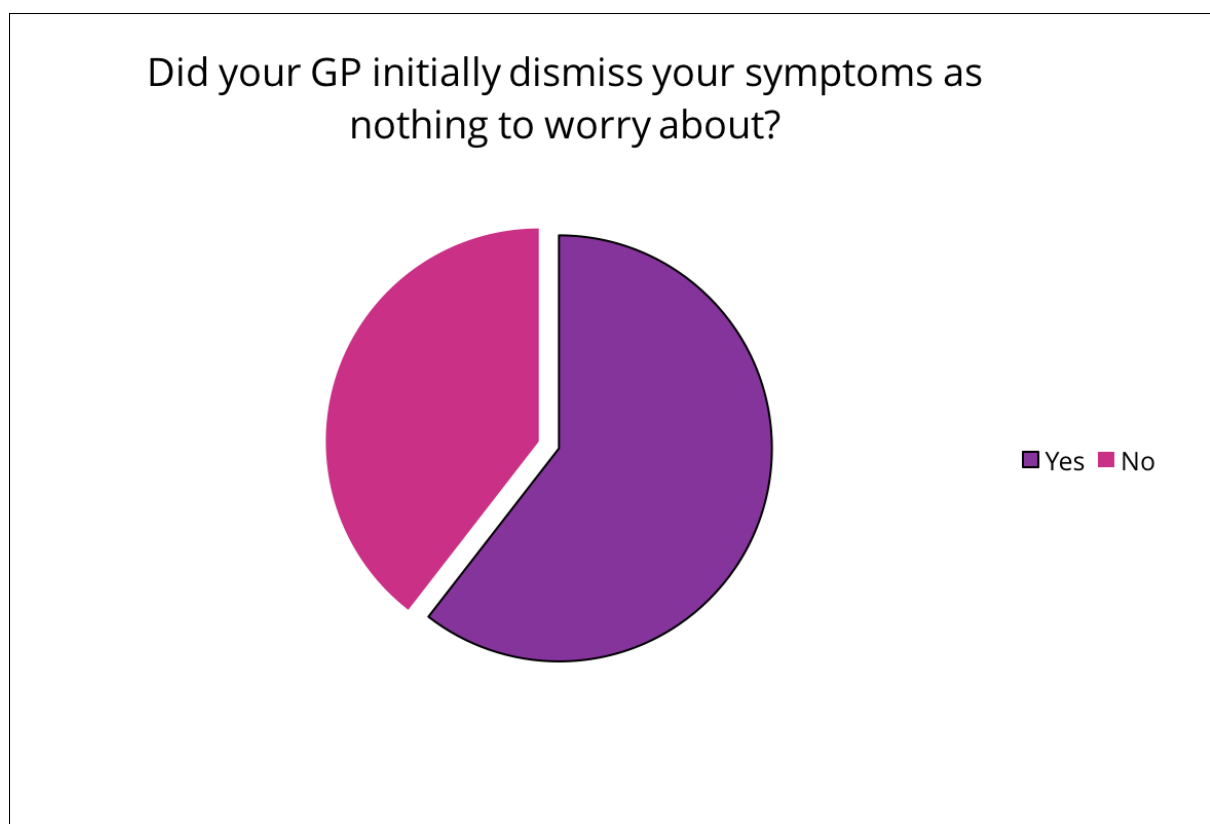
* Total > no of respondents as some listed more than one symptom as their initial symptom

Abdominal, back pain and jaundice were reported in half of respondents as the major initial symptoms that people first reported to their doctors. Indigestion, weight loss and change in bowel habit were next.

Dismissal of symptoms

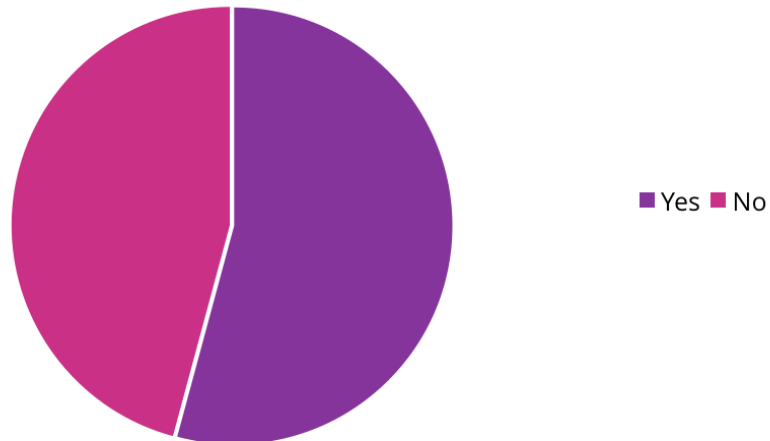
Respondents were asked if their GP or they themselves initially dismissed their symptoms as nothing to worry about.

Nearly 2/3 of respondents (61%) said that their GP initially dismissed their symptoms – this is an increase of around 10% on our 2013 survey.



Over half (54%) of respondents said that they also initially dismissed their symptoms as nothing to worry about

Did you initially dismiss your symptoms as nothing to worry about?



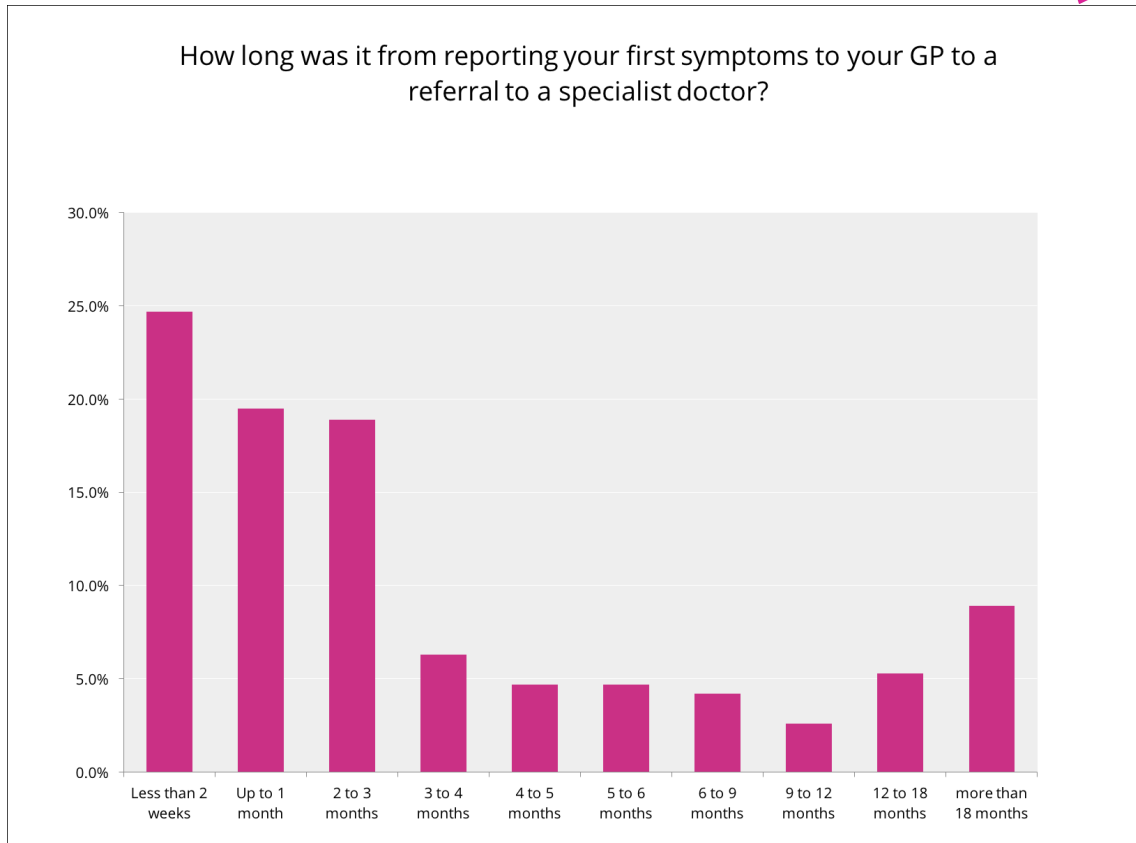
Route to diagnosis

When asked how long it was between reporting their first symptoms to a GP and a referral to a specialist, one quarter said less than two weeks (down from one third in 2013) with one in five having to wait a month.

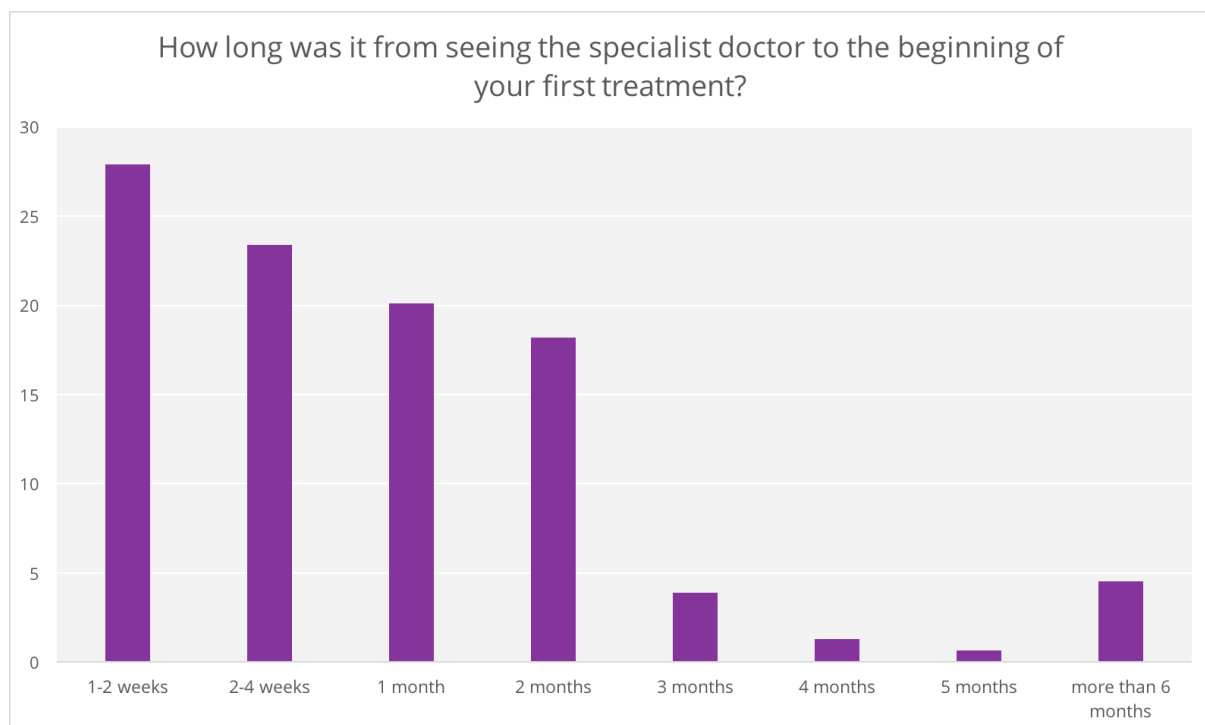
Nearly one third had to wait four months or more with 14% having to wait 12 months or more.

For those not referred by a GP:

- nearly two thirds were diagnosed as a result of an emergency presentation to Accident and Emergency,
- 21% via another outpatients department
- 18% opted to get a private referral (usually due to the length of wait for imaging tests)



For those referred, nearly two thirds began treatment within a month of their referral to a specialist with 23 per cent waiting two months or more. 18 per cent were not referred for treatment.



Stage at diagnosis

Respondents were asked what stage they were told they were at diagnosis:

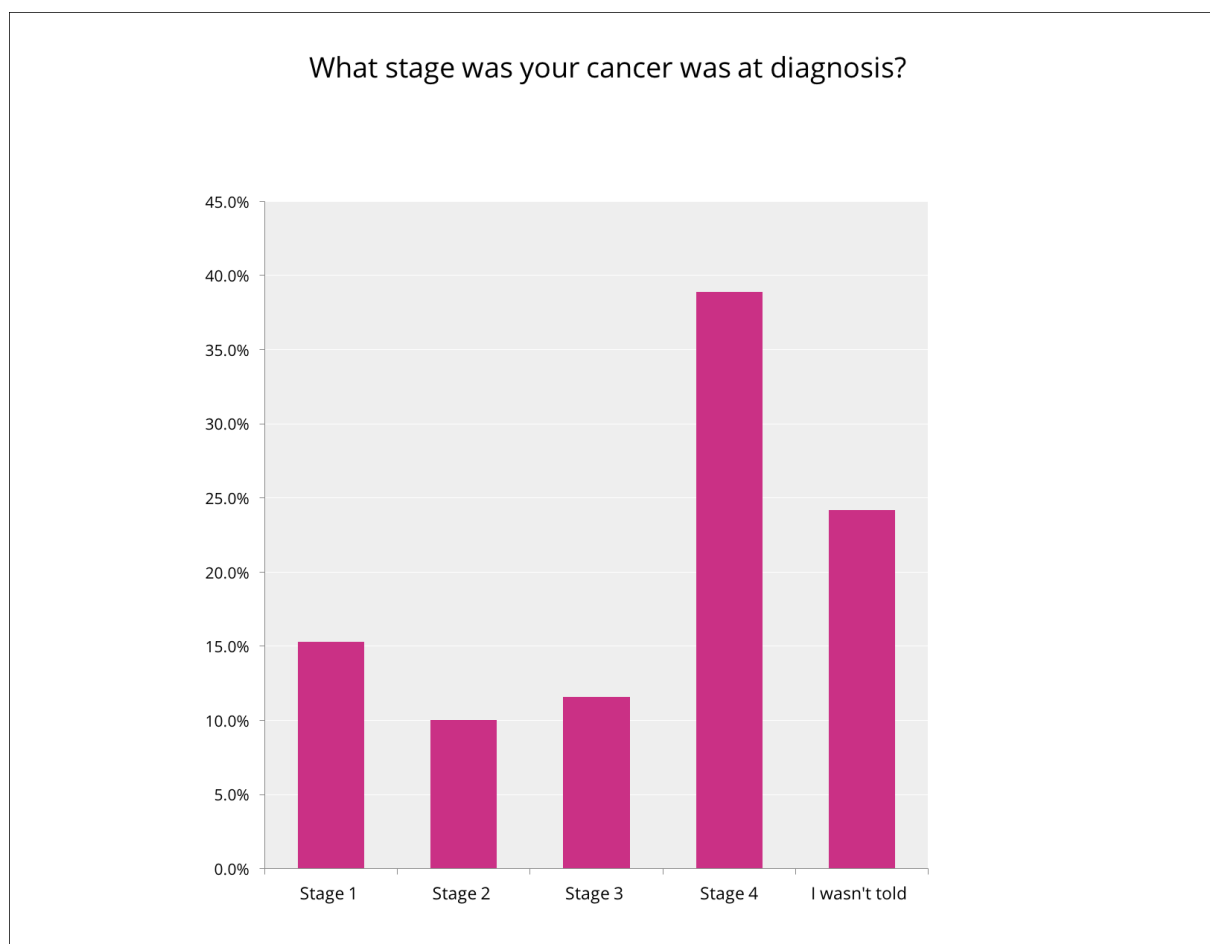
15% = **Stage 1** (cancer confined to pancreas and hasn't spread to nearby organs)

10% = **Stage 2** (cancer confined to pancreas but local lymph nodes may be affected)

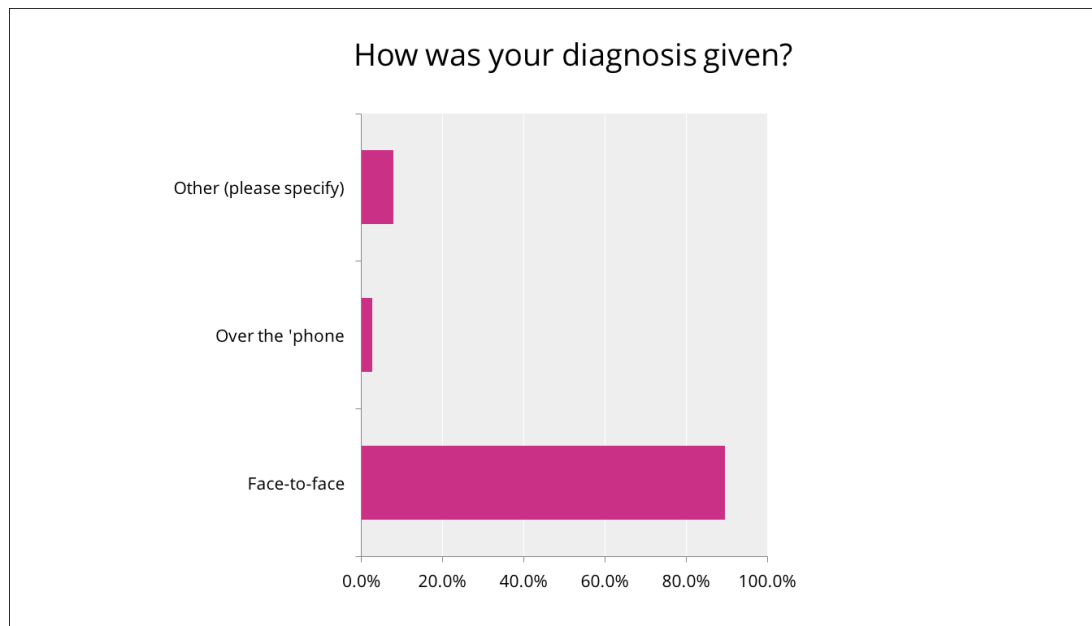
12% = **Stage 3** (an inoperable tumour involving large blood vessels - there may be spread to lymph nodes)

39% = **Stage 4** (cancer has spread to other organs such as the liver, lungs or lining of abdomen - metastatic disease)

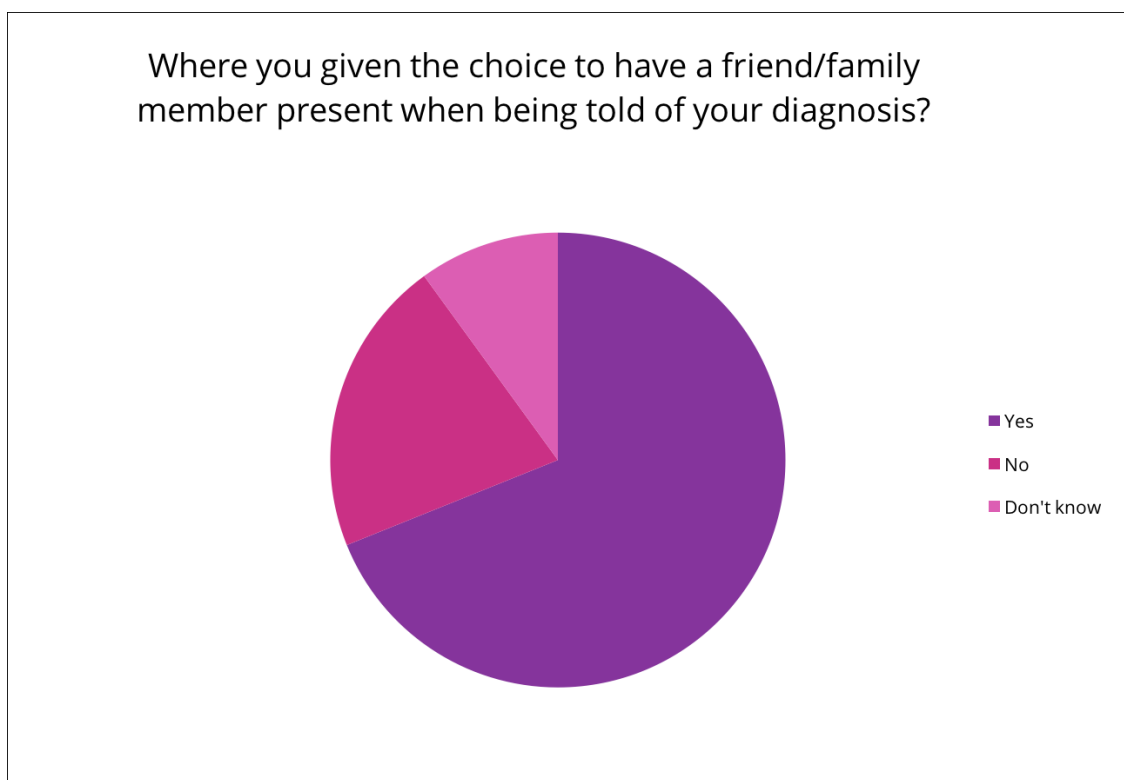
Nearly one quarter were not told the stage of their cancer.



How respondents were told of their diagnosis



Nearly 90% of respondents had a face-to-face conversation when being told of their diagnosis. Over two thirds were able to have a family member or friend present however, one in five were not given that choice.

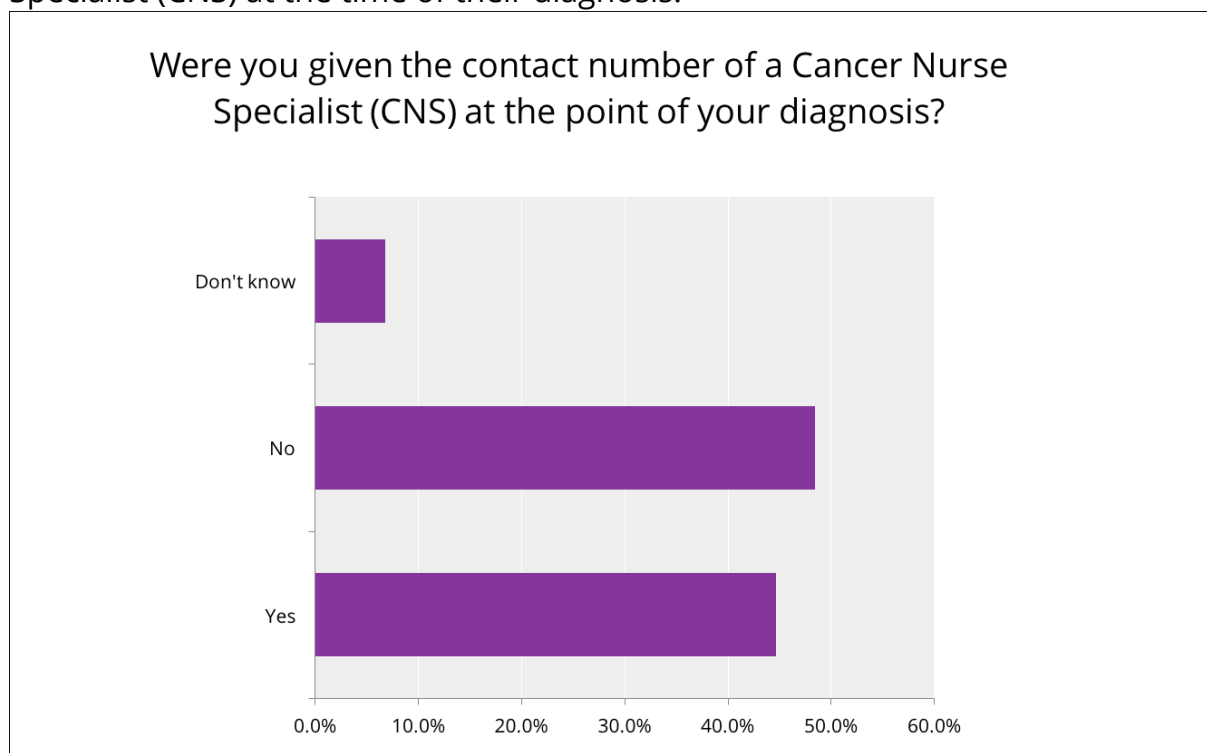


The majority of respondents were given enough time to discuss their diagnosis with their health professionals (63%), but over one in five said they were not given enough time.



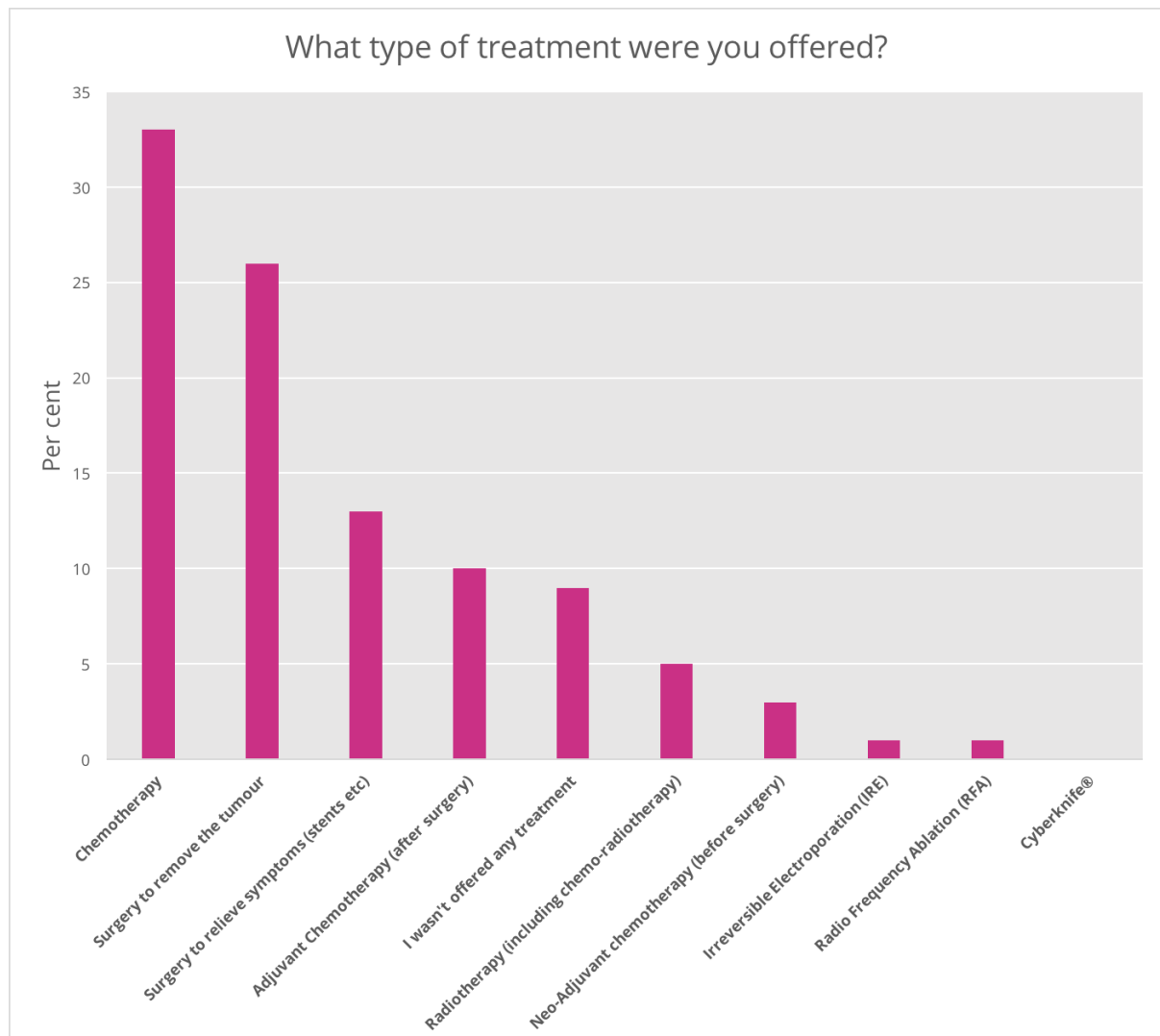
Access to a Cancer Nurse Specialist (CNS)

Nearly half of respondents were not given contact details for a Cancer Nurse Specialist (CNS) at the time of their diagnosis.

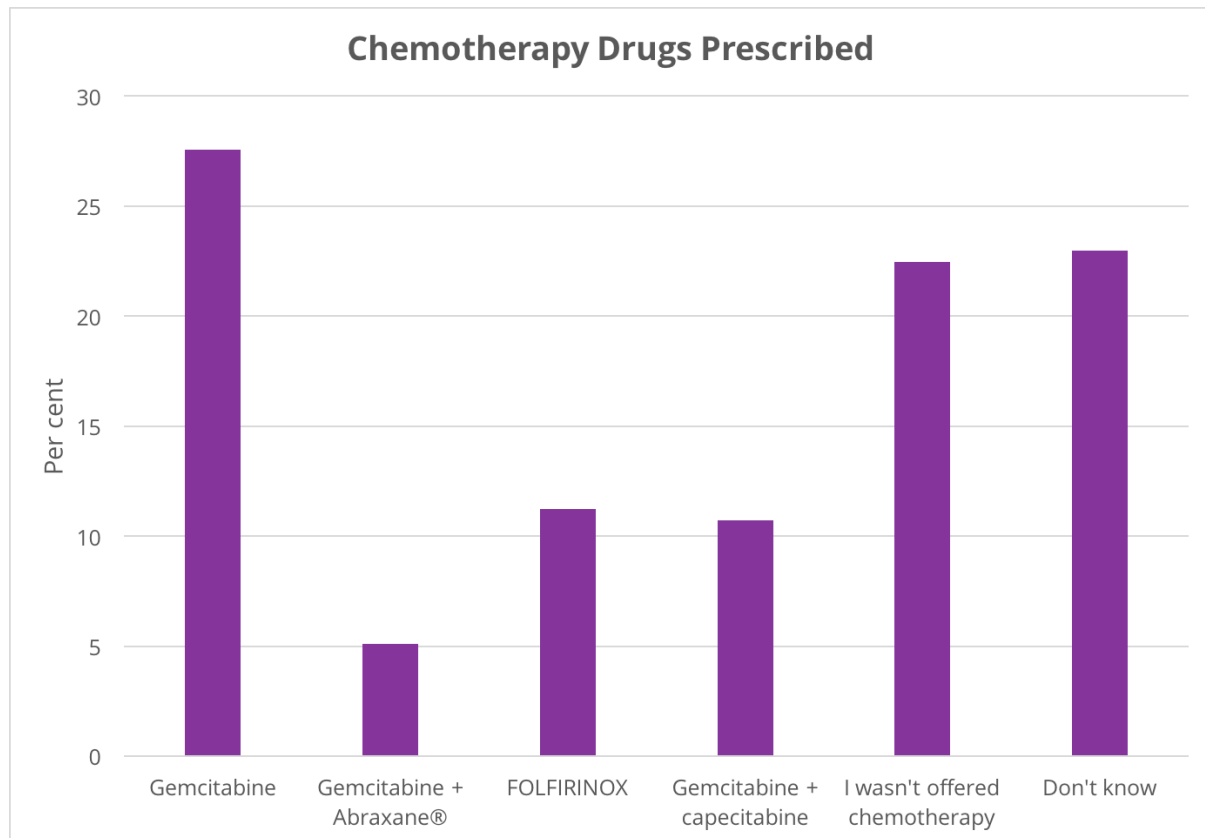


Treatments

The majority of pancreatic cancer patients were offered chemotherapy treatment. In our survey, there were a high number receiving treatment for operable pancreatic cancer. Of those who selected 'other' over half stated that the disease was far too advanced for any treatment to be an option.



Chemotherapy drugs prescribed



The majority of respondents (just over a quarter) who were offered chemotherapy were treated with gemcitabine alone.

Over one in five were not offered chemotherapy at all, 16 per cent were treated with a gemcitabine combination (either with Abraxane or capecitabine) and one in ten were treated with FOLFIRINOX combination.

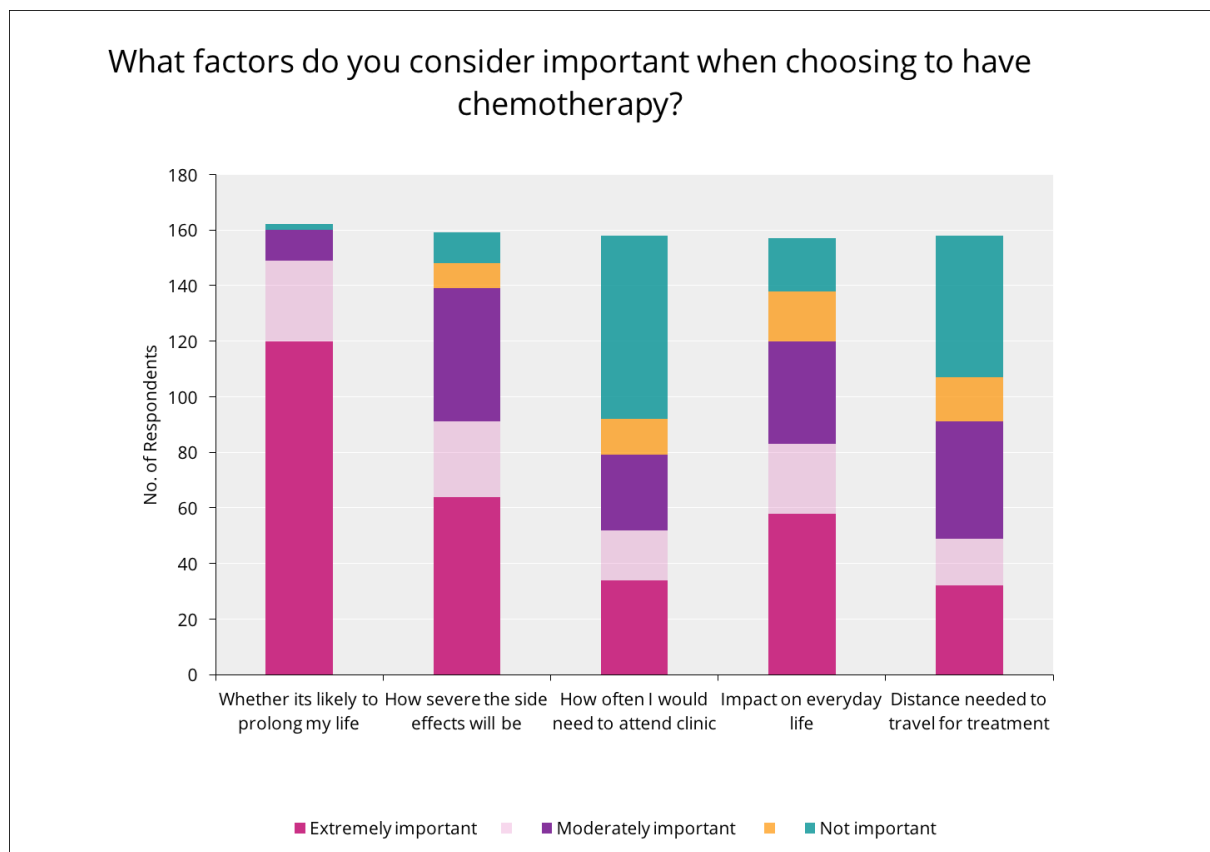
Over one in five were unable to recall the name of the chemotherapy regimen.

Choosing to have chemotherapy treatment

We asked respondents on a scale of extremely important to not at all important what factors were important in deciding whether to have chemotherapy treatment.

Whether it would prolong life (75%), how severe the side effects will be (40%) and the impact in everyday life (37% were cited as being extremely important considerations.

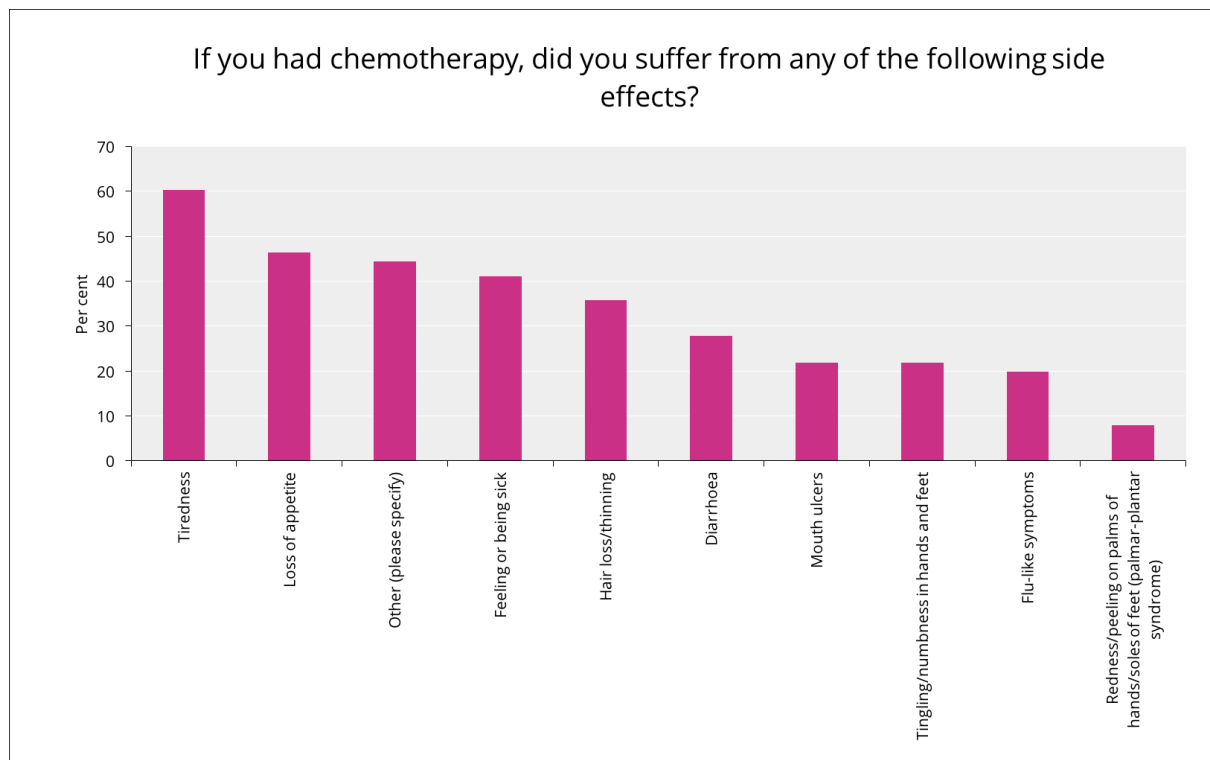
How often they needed to attend clinic and the distance needed to travel for the treatment were not considered to be as important.

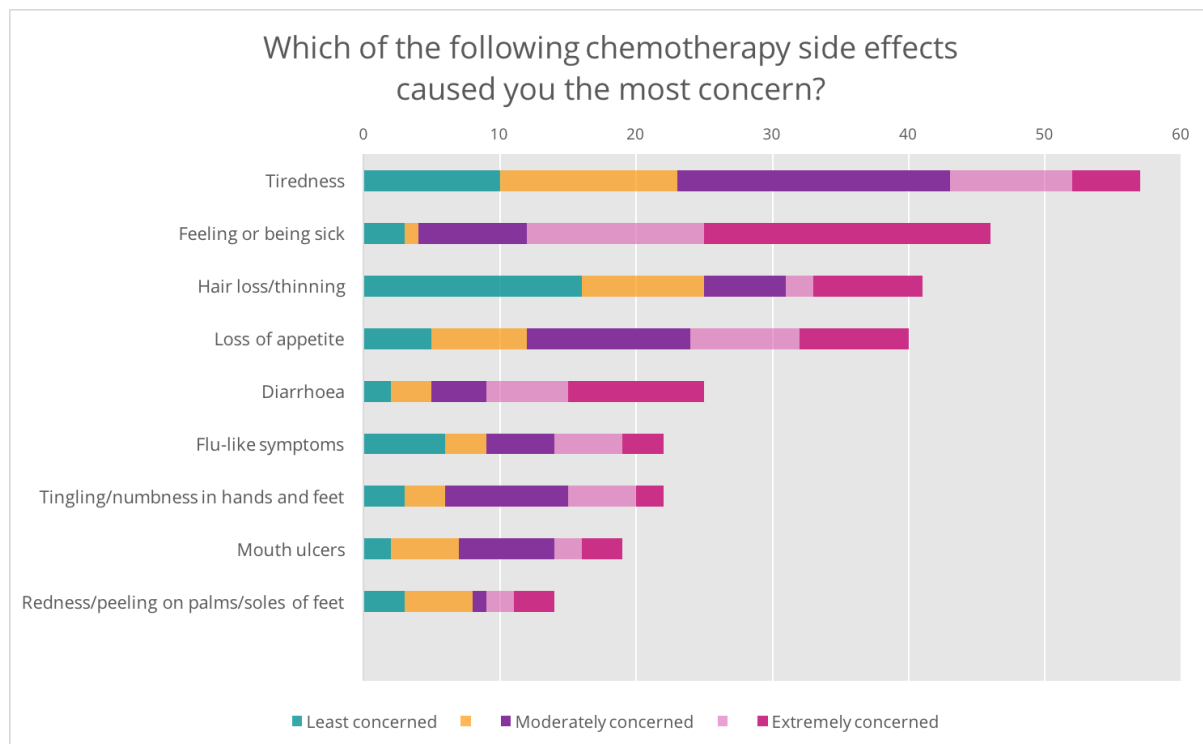


Side effects

Over two thirds of respondents cited tiredness as being the main side effect of chemotherapy treatment they suffered from with loss of appetite, feeling or being sick hair loss and diarrhoea being the other main side effects reported.

Of the 'other' category, two thirds stated no chemotherapy was offered or it was 'too late for chemotherapy', but other side effects listed included constipation, change in taste, rash, dehydration, dry skin, hallucinations and swelling of limbs.





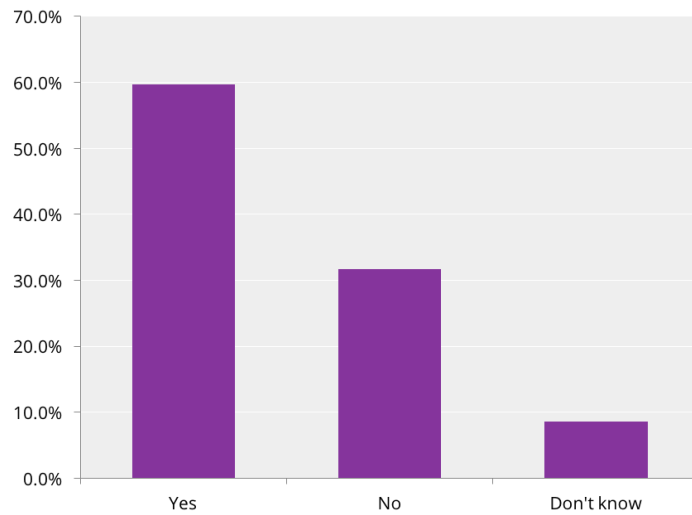
The side effects that most respondents were concerned with were feeling or being sick, loss of appetite diarrhoea and tiredness. Hair loss was not of a concern to most.

Patient information

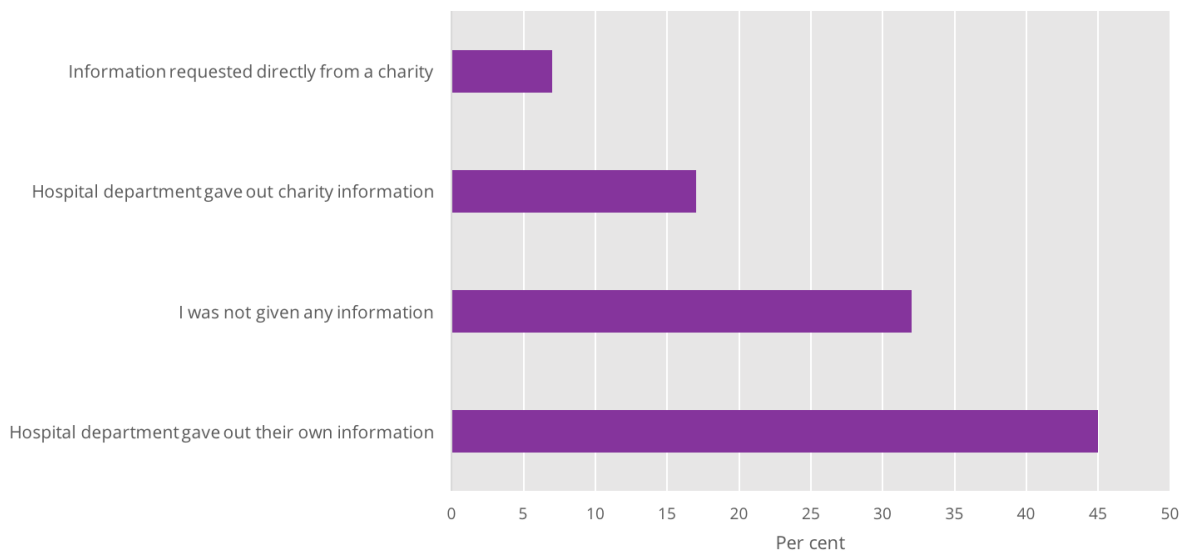
It was encouraging to see that just under two thirds (60%) of patients were given patient information about pancreatic cancer in written form to take home with them. However, 40 per cent of patients still do not receive any written patient information.

Of those given information, two thirds were given information written by the hospital department, one quarter were given charity-written information by their hospital team and one in ten went directly to a charity to get written information.

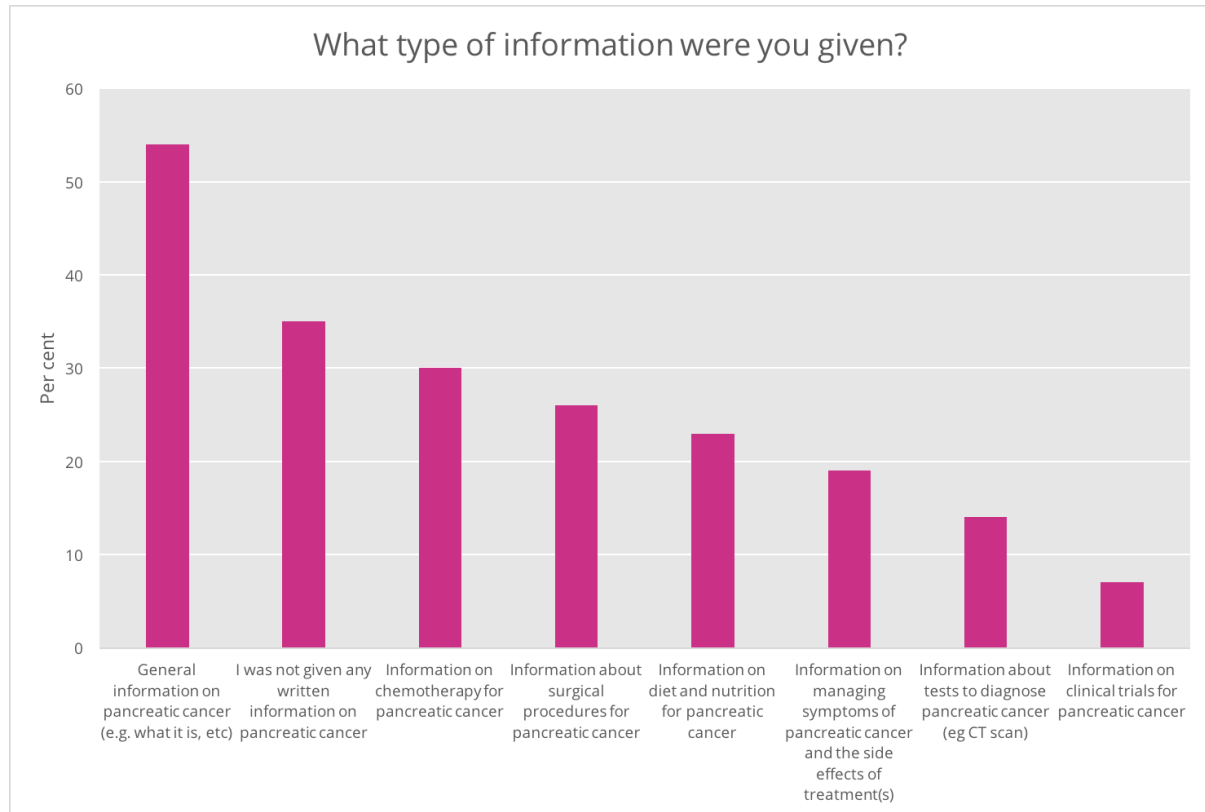
Were you given written information about pancreatic cancer and your treatment(s) to take home?



Who provided this information?



Of those who were given patient information, most were given general information on the disease itself. Only six per cent were given any written information on clinical trials for pancreatic cancer.



Emotional Support

Since their diagnosis, over half of respondents have had to seek emotional support.

