



**NET Patient Foundation  
Patient Experience Survey 2015**



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## 1. Executive summary

Each year in the UK, around 5 in every 100,000 people are diagnosed with neuroendocrine tumours (NETs). Neuroendocrine tumours are uncommon and because of their nature, gathering data to look at patients' experience of care and treatment is very challenging.

In 2014, the NET Patient Foundation commissioned Quality Health to undertake a survey of people who were undergoing treatment for neuroendocrine cancer. The survey aimed to gain valuable data on the diagnosis, treatment and care of, and information and support services for neuroendocrine cancer patients in order to improve the quality of health services for future patients.

Because of the difficulty in identifying NET patients, samples were drawn by working directly with 7 NHS Trusts in England providing specialist NET treatment.

The 7 NHS Trusts which took part in the survey were:

- Imperial College Healthcare NHS Trust
- King's College Hospital NHS Foundation Trust
- Oxford University Hospitals NHS Trust
- Royal Free London NHS Foundation Trust
- The Christie NHS Foundation Trust
- The Royal Liverpool and Broadgreen University Hospitals NHS Trust
- University Hospitals Coventry and Warwickshire NHS Trust

The process was slow and the send out was therefore carried out between January and September 2015. The questionnaire was posted to patients, with reminders and a follow-on survey sent to those who did not respond.

This report presents the results of the survey and forms part of a wider piece of work mapping services across the UK.

The survey covered a range of topics including: how long it took for patients to be diagnosed; what their symptoms were; what tests they undertook; and what information and support they received.

In total, 996 people responded to the survey. This was 56% of a total sample of 1849 people. This is a good response rate and a statistically valid sample. However, it's slightly lower than the response rate to the national cancer patient experience survey (typically around 64%), which may be because of the length of time which has elapsed between treatment and patients receiving the questionnaires.

The survey results provided important data, covering a range of themes related to the care and treatment of neuroendocrine cancer patients. We have included direct comparisons with data from the 2014 National Cancer Patient Experience Survey (CPES) where this is possible. There are some stark differences between the

experiences of NET patients compared to all cancer patients who completed the 2014 CPES. Some key themes are listed below:

### **Diagnosis**

It takes far longer for NET patients to be diagnosed and they will see their GP more often; will be misdiagnosed or treated for another condition; and their condition is more likely to get worse before treatment starts

- NET patients have to see their GP far more often than other cancer patients before they are referred on to hospital – only 44% of NET patients see their GP once or twice before referral; whereas for other cancer patients this is 75%
- Just over half of NET patients (58%) see a hospital doctor within 3 months of noticing that something may be wrong; compared to 78% of other cancer patients
- NET patients are less likely to think they are told they had cancer sensitively – 74%, compared to 84% of all cancer patients
- More NET patients said their health got worse between first seeing their GP and starting cancer treatment (38%) compared to other cancer types (20%)

### **Information and explanations**

NET patients are less likely to receive written information (and to understand it) in all stages of their treatment and care, whether at diagnosis, during tests, about their type of cancer and about side effects. They are also far less likely to understand the explanations they are given about all aspects of their cancer treatment

- Only half of NET patients said they were given written information about all of their tests – compared to 91% of all cancer patients who say they received written information
- Less than half (47%) of NET patients said they received written information about their type of cancer that is easy to understand; compared to 72% of other cancer patients
- Far fewer NET patients said they understood the explanation of what was wrong with them (47%) than other cancer patients (73%)
- Fewer NET patients said that side effects of treatment were definitely explained in a way they could understand (60%); compared to 75% of other cancer patients
- Just over half of NET patients (57%) said they received written information on side effects of treatment; compared to 82% of other cancer patients
- Fewer NET patients said they were given enough information about their condition and treatment (71%); compared to 88% of other cancer patients

## **Treatment and Care**

NET patients are less likely to respond positively to questions about their treatment and care than other cancer patients including on whether they think their views are taken into account and whether they feel involved in decision making

- Fewer NET patients thought their views were taken into account when doctors and nurses were discussing what treatment they should have (60%), compared to other cancer patients (71%)
- Fewer NET patients felt involved in decisions about their treatment and care (63%); compared to 72% of other cancer patients

## **NET Clinical Nurse Specialist**

NET patients are less likely to have access to a clinical nurse specialist, although those who do, rate their care very highly

- Just under three-quarters of respondents (74%) had access to a Clinical Nurse Specialist (CNS) who was an expert in neuroendocrine cancer – compared to 89% across all cancer types in the CPES. This is a significant finding. For the 2014 National Cancer Patient Experience Survey in England, we carried out detailed analysis of the impact of this question on other responses. In that survey, patients who said they did have a Clinical Nurse Specialist were more likely to give positive responses to virtually every other question in the survey.
- Of those who had a CNS almost all respondents (97%) had trust and confidence in them and 99% of respondents said that they had a good awareness of their cancer

## **Support for people with a NET Cancer**

NET patients are less likely to receive information on getting support than other cancer patients, including on networks and self help groups as well as charities

- Over half of respondents (54%) were not offered information on support or self-help groups for people with neuroendocrine cancer; this is far higher than for the CPES where 17% of patients were not offered this information
- Over half of respondents (53%) felt as if they were not given any information on the impact their cancer could have on their work life or education; again, this is far higher than for the CPES where 25% felt they were not given this information
- 60% of respondents did not receive help from a cancer charity
- Only half of NET patients said they were definitely given enough emotional support (50%); compared to 70% of other cancer patients

### **Support from GPs**

NET patients are less likely to respond positively when asked about care and support from their GP including on whether their GP had enough information about their care and treatment; and on whether their GP did everything they could to support them

- Under half of respondents (43%) felt their GP had a full understanding of their cancer and 15% reported that their GP had no knowledge of neuroendocrine cancer
- Fewer NET patients said their GP had enough information about their care and treatment in hospital (86%); compared to 95% of other cancer patients
- Just over a half of NET patients (54%) said that their GP and general practice staff did everything they could to support them; compared to 66% of other cancer patients

### **Overall NHS Care for NET Cancer**

NET patients report a less positive overall experience than other cancer patients and are more likely to say that they feel they are treated as a set of cancer symptoms rather than a whole person

- The majority of respondents reported a positive overall experience of their care with 83% of respondents reporting that it was either excellent (47%) or very good (36%). However, the 2014 national cancer patient experience found that in all types of cancers 89% of respondents rated their overall experience of care as excellent (57%) or very good (32%). Again, this is a significant finding, suggesting that NET patients are overall less happy with the care they receive from NHS services.

### **Next steps**

The postal survey results which are detailed in this report form the first part of a longer study which will continue to collect data from other NHS trusts across the UK on the services and treatment they provide for NET patients. The findings of this national census will be published in 2016.

## **2. Background and methodology**

### **2.1 Introduction**

This survey was initially publicised in a letter in May 2014 from the NET Patient Foundation, to leading clinicians responsible for the treatment of neuroendocrine cancers in 8 NHS Trusts in England providing care for these patients.

The rationale for the survey builds on the experience of the Cancer Patient Experience Survey (CPES) programme, run by the Department of Health and subsequently NHS England since 2010, which has been highly successful in identifying gaps in provision across cancer services; lack of information and support for patients; and specific areas of concern for those with particular kinds of tumours.

This survey of patients with neuroendocrine cancers was necessary because it is not possible to identify patients with NET cancers in the cohort of respondents from the CPES. Almost no NET cancers have specific International Classification of Disease Codes and it is therefore not possible to identify NET patients within CPES respondents. There are, therefore, no breakdowns for NET patients available in that dataset. As a result, this separate survey was commissioned by the NET Patient Foundation to identify the experiences of patients, working with specialist Trusts who provide care for these patients.

### **2.2 Questionnaire design and development**

The design of the questionnaire generally follows that of the National Cancer Patient Experience Survey, with some amendments and additions to ensure that the questionnaire was as relevant as possible to NET patients and their experiences. For example, the questionnaire included reference to specific symptoms which NET patients experience; and has more questions around the diagnosis pathway, given that this is typically longer and more complicated than some of the more common cancers.

The questionnaire then underwent a process of cognitive testing with NET patients who volunteered their time to complete and make comments on the content and design. Following this testing, some amendments were made and the final questionnaire was ready to send out towards the end of 2014.

## 2.3 Sampling and data collection

The survey eventually covered 7 NHS trusts in England that provide specialist cancer services for patients with neuroendocrine cancers. Adult patients (aged 16 and over) with a confirmed diagnosis of neuroendocrine cancer who have been admitted to hospital as inpatients, or who were a day case patient or received their treatment in an outpatient setting and have attended between 1st August 2011 and 31st July 2014 were included in the survey.

The survey was conducted by post, with two reminders (to non-responders only) as is the case with the national CPES. A standard questionnaire, covering letter and reminder letters were used.

## 2.4 Timescales

The send out of the survey began in early January 2015 and ended in September 2015. Once the sample had been provided by the trust and rigorous checks carried out on the data, the send out was begun for each trust on an individual basis. This was because some trusts uploaded their data far quicker than others.

Once send out had begun, the fieldwork period for each trust followed the normal CPES timescales and covered a 12 week period from first send out to closing the survey. As each of the trusts uploaded at different times a staggered approach was taken. The final trust's fieldwork ended at the beginning of September 2015.

## 2.5 Response rate

The overall response rate was 56% - a total of 996 responses from a sample of 1849. But there were significant differences in response rates and sample sizes between trusts. The variance between the 7 trusts taking part is as follows:

<b>Trust</b>	<b>Total sample</b>	<b>Number of responses</b>	<b>Response rate</b>
Imperial College Healthcare NHS Trust	117	27	24%
King's College Hospital NHS Foundation Trust	350	211	63%
Oxford University Hospitals NHS Trust	151	89	59%
Royal Free London NHS Foundation Trust	858	451	54%
The Christie NHS Foundation Trust	166	116	72%
The Royal Liverpool and Broadgreen University Hospitals NHS Trust	107	55	53%

University Hospitals Coventry and Warwickshire NHS Trust	100	47	50%
<b>TOTAL</b>	<b>1849</b>	<b>996</b>	<b>56%</b>

### 3. Survey results

Please note that we have included the corresponding results for the 2014 Cancer Patient Experience Survey (broken down by tumour group, and for all cancer types) in the charts where a direct comparison can be made.

## Respondent characteristics

### 3.1 Ethnic origin

87% of respondents identified as being white British; 1% Irish; 4% white 'other' and 7% as black, Indian or another minority ethnic group.

### 3.2 Age

8% of respondents were aged between 25 and 44; 42% were aged between 45 and 64; and 50% were aged over 65. There were no respondents who were under the age of 24. The chart below shows the age breakdown in more detail:

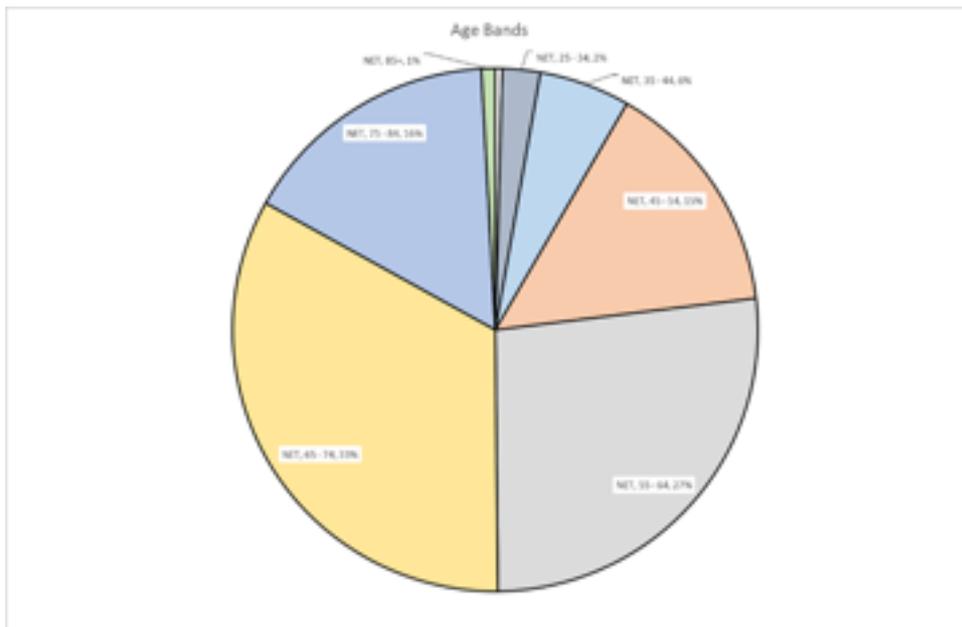


Fig.1 Age groups of respondents

### 3.3 DIAGNOSIS

This section of the survey asked patients about their diagnosis: how long it took, the actions their GP took; whether they were treated for another condition.

### 3.4 Before diagnosis

We asked respondents how many times they had visited their GP before they were told they needed to go to hospital about cancer. 20% of respondents didn't see their GP at all. Of those who did, just over a third saw their GP more than 5 times (35%); just under a quarter (22%) said 3 or 4 times; and 44% saw their GP either once or twice.

In the national CPES, 75% of people said they saw their GP either once or twice. And there was significant variation between tumour groups, with sarcoma scoring the lowest in that survey (59%) for numbers seeing their GP once or twice.

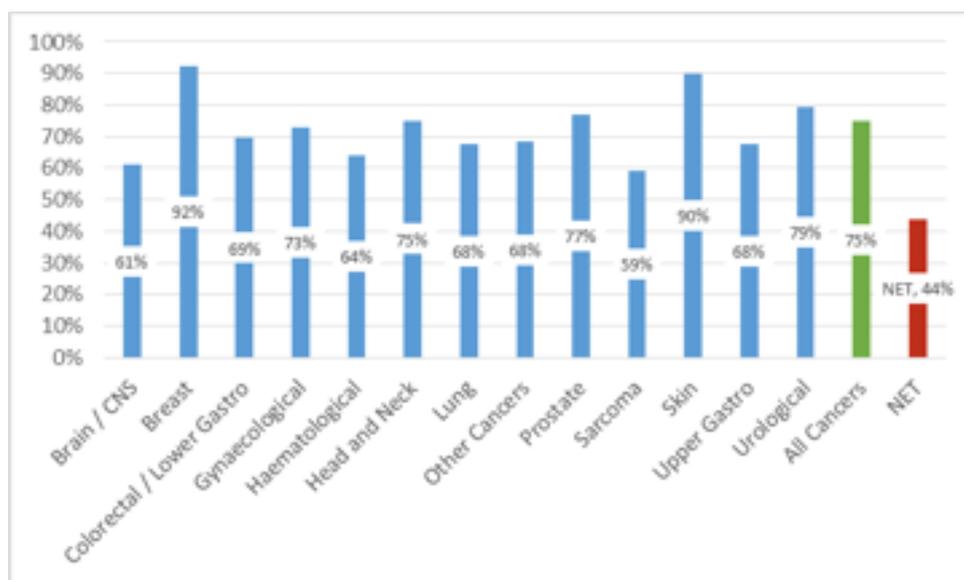


Fig.2 Proportion of respondents seeing their GP only once or twice before being told they needed to go to hospital about cancer

### 3.5 Main health problem

We asked what the main health problems or symptoms respondents had before they were diagnosed with neuroendocrine cancer. These were specifically the health problems or symptoms which took them to the doctor. Pain and discomfort in their tummy was by far the most common, with 41% of people saying they experienced this. This was followed by diarrhoea/constipation (35%), and extreme tiredness/fatigue (28%).

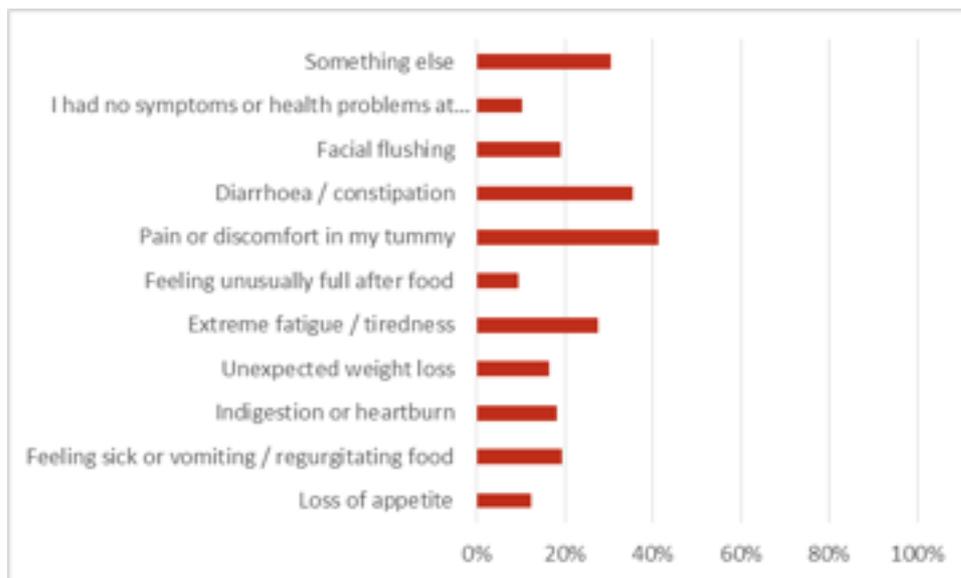


Fig.3 Main health problem which took them to see a doctor

### 3.6 What the GP did

We asked respondents if they went to see a GP about these health problems or symptoms what was the first thing that the GP did? We asked them to tick the option which most closely matched their GP's first action.

Nearly a quarter (23%) of people said that their GP started treating them for another condition. 28% of people said that their GP sent them to have further tests.

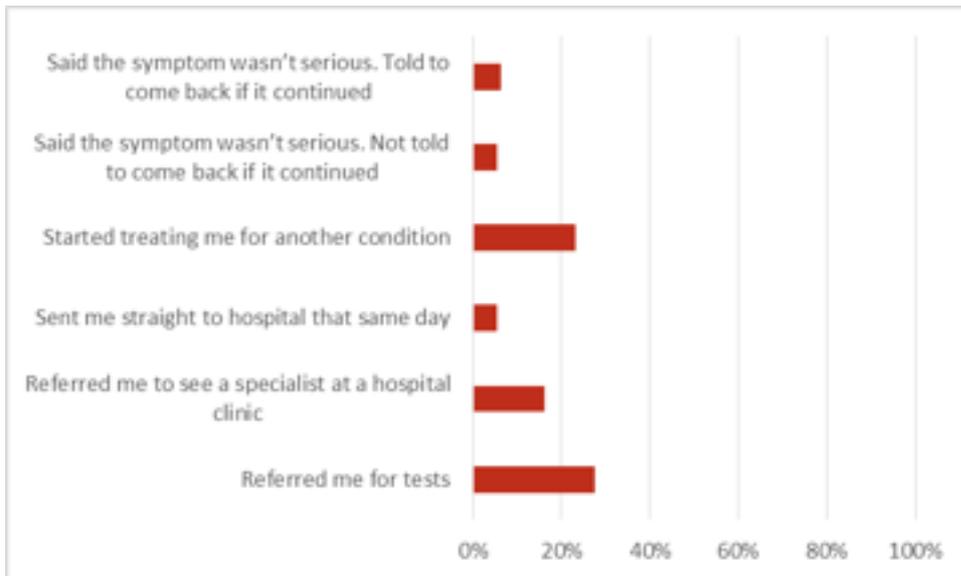


Fig.4 What the GP did when they went to see them about their health problem or

### 3.7 Treatment for other conditions

We then asked the people who had been treated for another condition, what this condition was. Most people said that this was irritable bowel syndrome (9%); followed by gastric or other stomach disorder (8%).

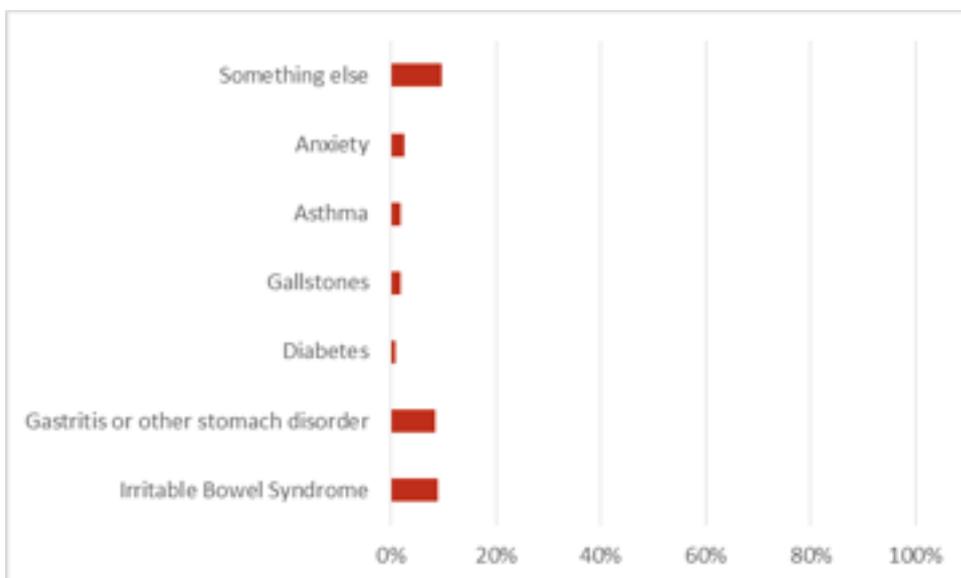


Fig.5 If treated for another condition, what was it

### 3.8 Length of time to see a hospital doctor

We asked respondents how they felt about the length of time it took before their first appointment with a hospital doctor. Just over half people said that they thought they were seen as soon as they thought was necessary (60%, while it was 83% in the national CPES); although one-fifth (20%) thought that they should have been seen a lot sooner.

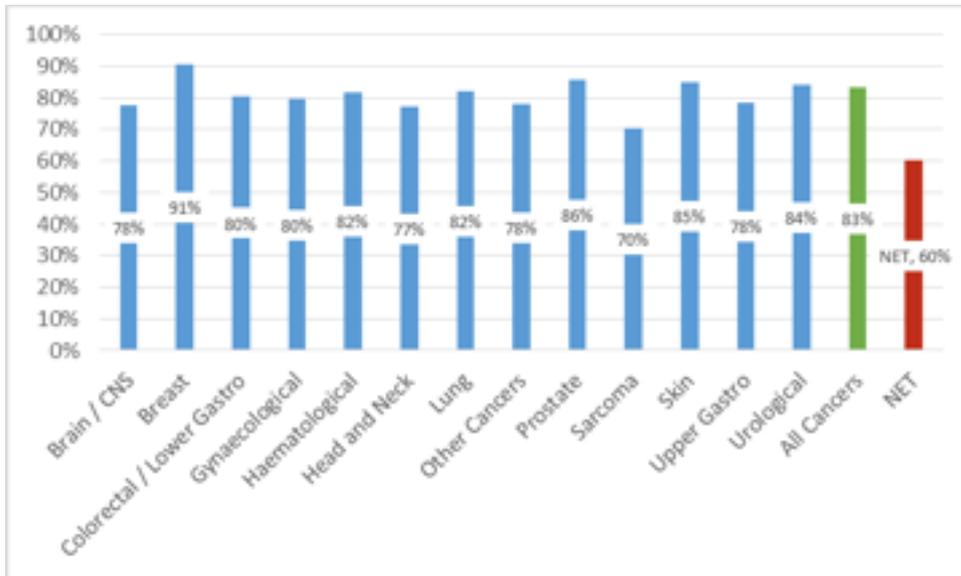


Fig.6 Proportion of respondents who thought they were seen as soon as necessary

### 3.9 Time between noticing symptoms to seeing hospital doctor

We asked respondents how long it was between first thinking that something might be wrong, to seeing a hospital doctor. For most people this was less than 3 months (58%, while it was 78% in the national CPES), followed by 3-6 months (14%, 11% in CPES). 6% of people said this was over 5 years.

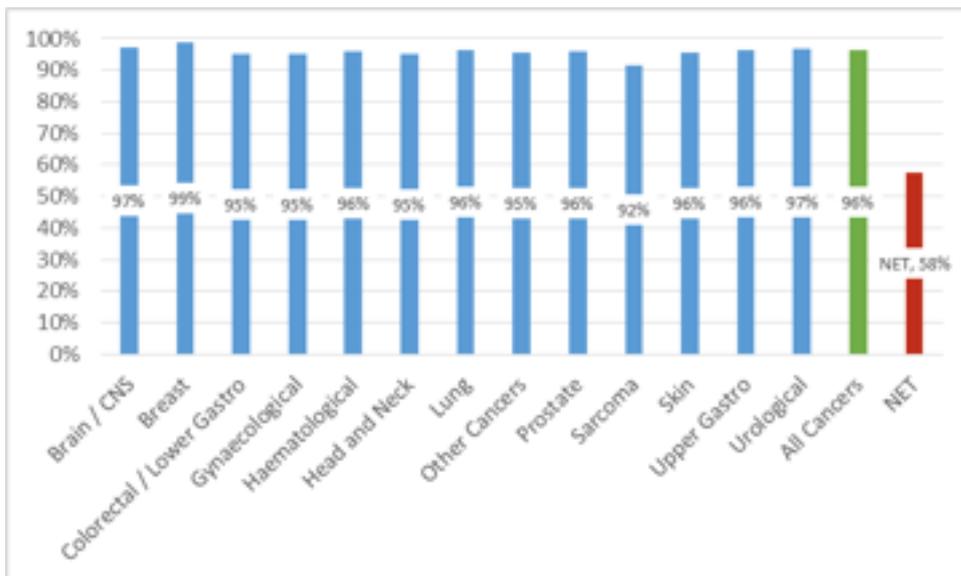


Fig.7 Proportion of patients saying they were seen by a hospital doctor within 3 months of thinking something was wrong

### 3.10 Investigation or surgery for another condition

We asked whether the respondent's cancer was discovered as a result of an investigation or surgery for another condition. Nearly three-quarters of people said this was the case (72%).

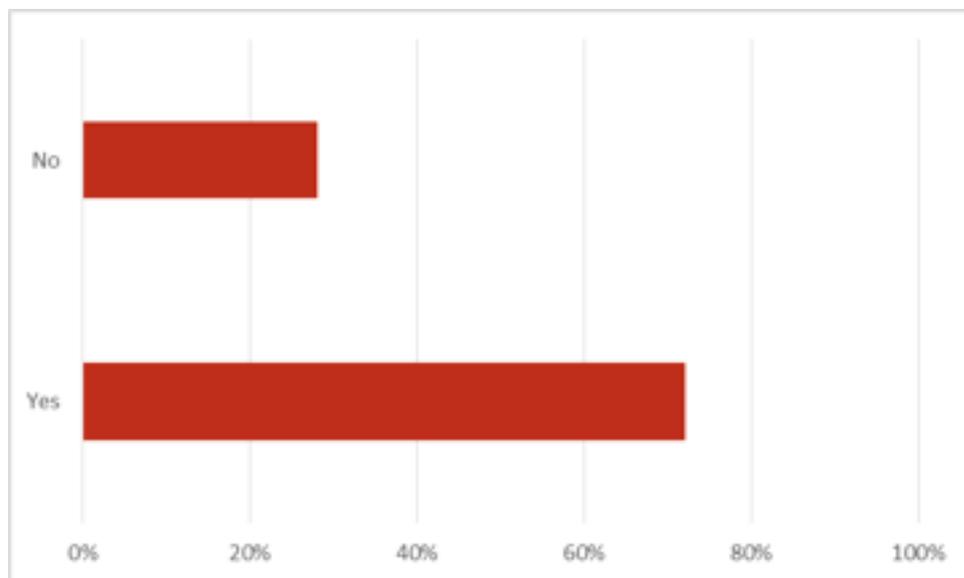


Fig.8 Proportion of patients saying their cancer was discovered as a result of an investigation for another condition

### 3.11 Location of diagnostic tests

Most respondents had their diagnostic tests in their local NHS hospital (81%). 9% has their tests in a specialist NET clinic in an NHS hospital; and 6% in a private hospital.

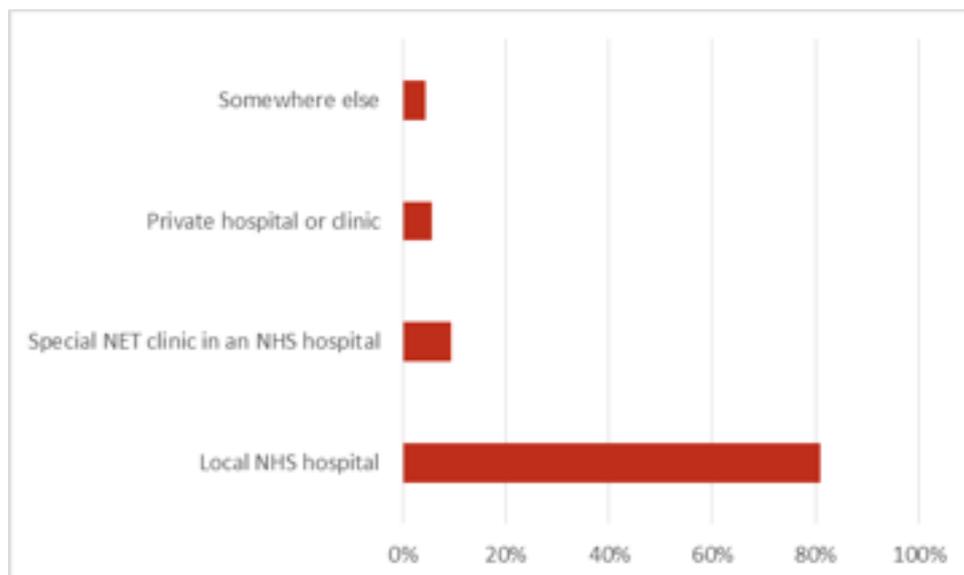


Fig.9 Where diagnostic tests were carried out

### 3.12

### Which diagnostic tests

Over two-thirds of people had blood tests (69%); and a 68% a CT scan; while 40% of people said they'd had an ultrasound scan and biopsy.

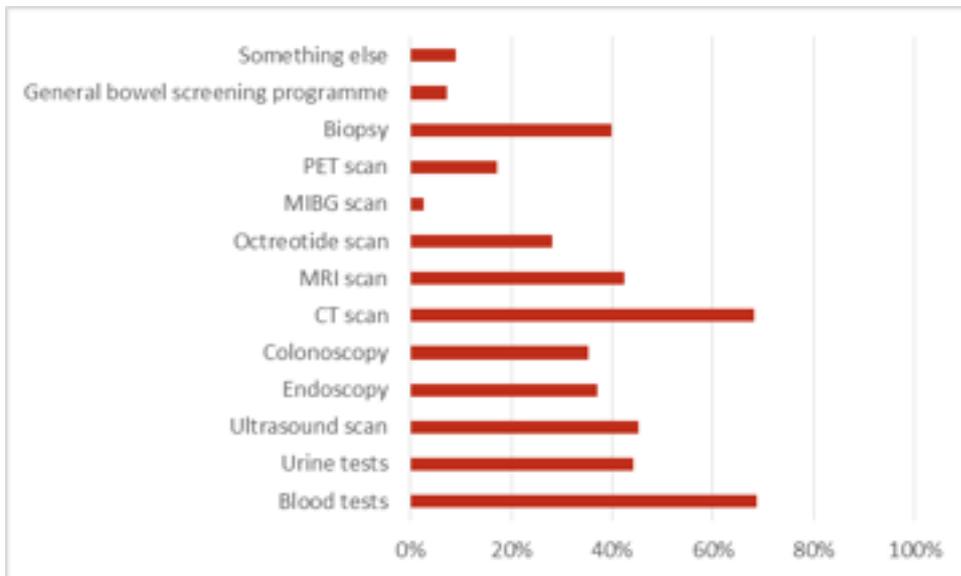


Fig.10 Which diagnostic tests patients had

### 3.13 Purpose of tests explained

Most people agreed that all of their tests were explained to them (80%). 6% of people said that none of their tests were explained to them.

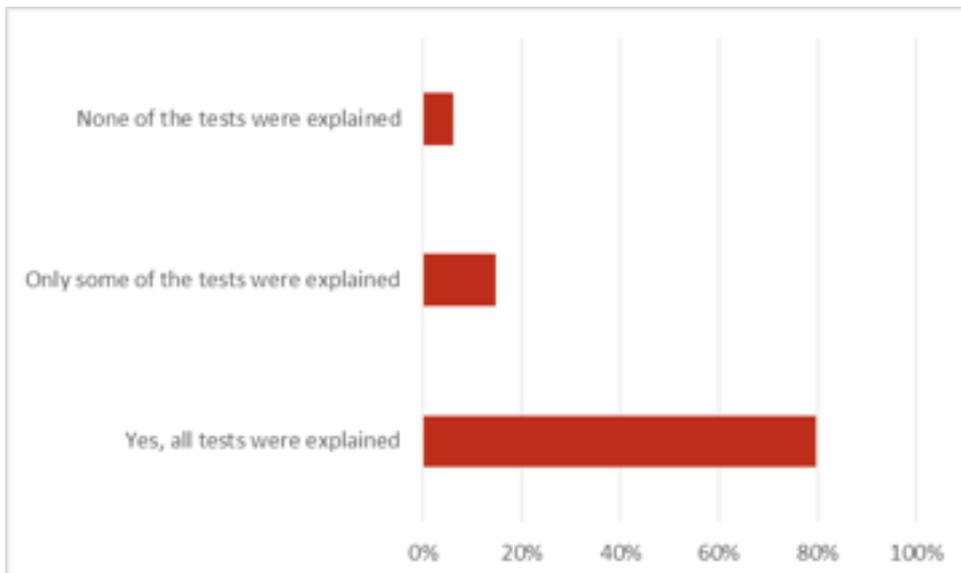


Fig.11 Proportion of patients saying diagnostic tests were explained to them

### 3.14 Explanation of test procedures

Again, most people said that the procedure for all of their tests was explained to them (85%). A small number (3%) said that they were not given an explanation for any of their tests.

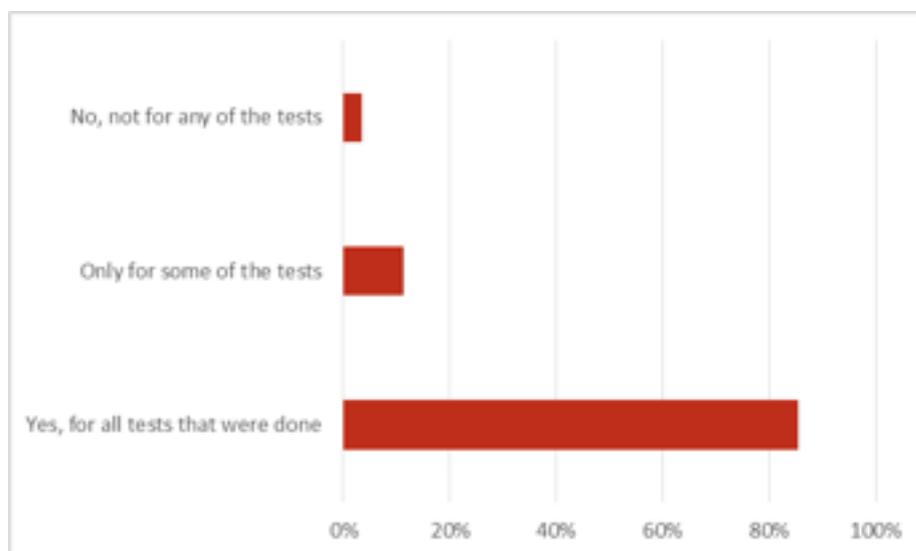


Fig.12 Proportion of patients saying test procedures were explained to them

### 3.15 Written information about tests

We asked respondents if they were given written information about tests beforehand. Exactly a half said that they were given written information for all of the tests they had (50%). However, 21% said that they were not given any written information for any of their tests.

While this question is not comparable to the national CPES survey because of differences in the response options, 91% of people answering the CPES had received written information.

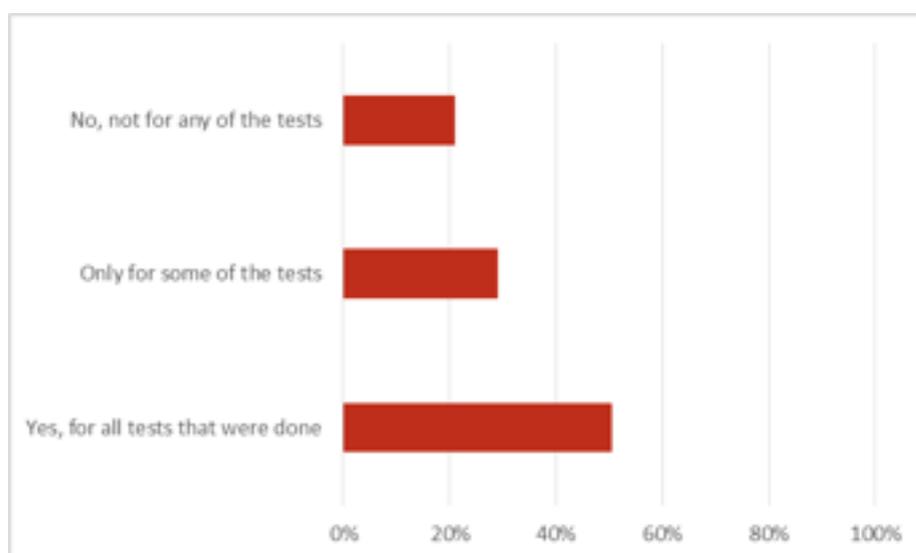


Fig.13 Written information about tests being received

### 3.16 Results of tests explained in an understandable way

77% of respondents said that the results of all their tests were explained in a way that they could understand. Nearly one-fifth (18%) said that this was only the case for some of their tests; and 5% said none of their test results were explained in an understandable way.

Again, this question was not comparable to the national CPES because of differences in the answer options, but in CPES, 78% said yes, their test results were explained in a way they could understand.

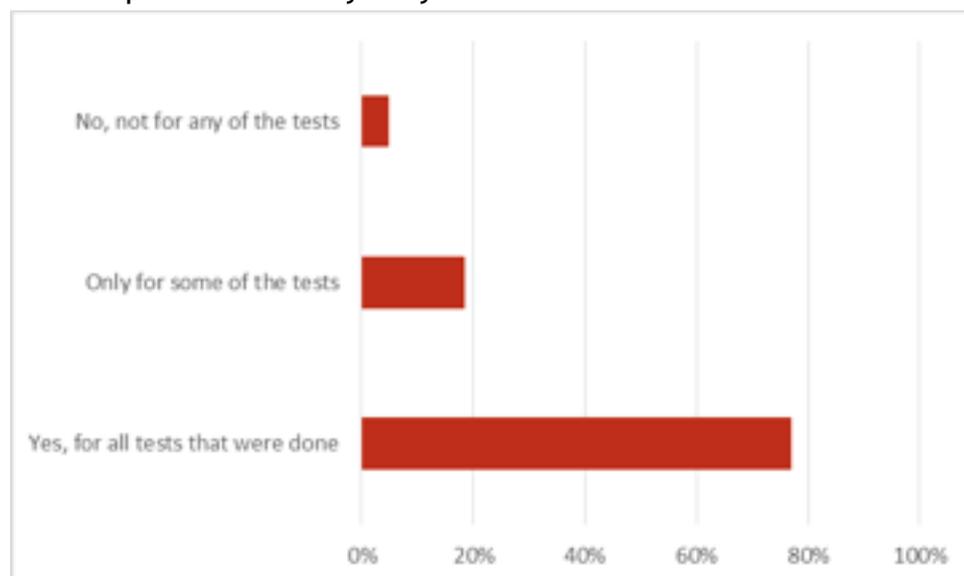


Fig.14 Test results explained in an understandable way

### 3.17 FINDING OUT WHAT WAS WRONG WITH YOU

This section of the survey asked patients about what happened when they found out what was wrong with them, including whether they were being treated for another condition; how sensitively they were told that they had cancer; whether or not they were given information when they were told.

### 3.18 When starting treatment what was it for?

We asked whether or not patients were told that they were being treated for neuroendocrine cancer when their hospital treatment first started. Nearly two-thirds (63%) said that they were told it was neuroendocrine cancer. Just over one-fifth (21%) were told that it was another condition - not cancer at all. And 16% were told it was another type of cancer.

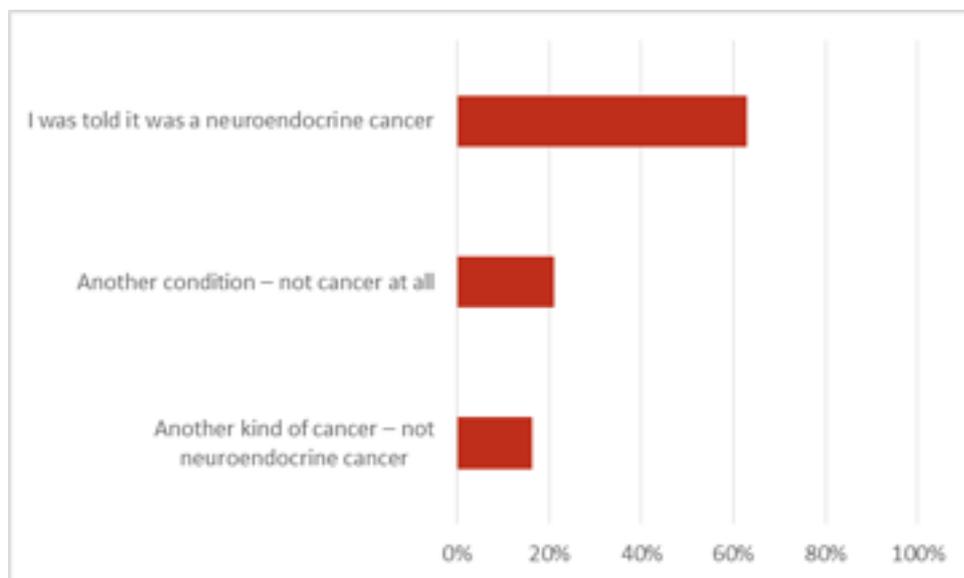


Fig.15 What patients were told they were being treated for

### 3.19

#### Being told sensitively

Nearly three-quarters (74%, while in the national CPES this was 84%) of respondents said that they were told that they had neuroendocrine cancer sensitively. 13% (19% in CPES) said it should have been done a bit more sensitively; and a further 13% (5% in CPES) said it should have been done a lot more sensitively.

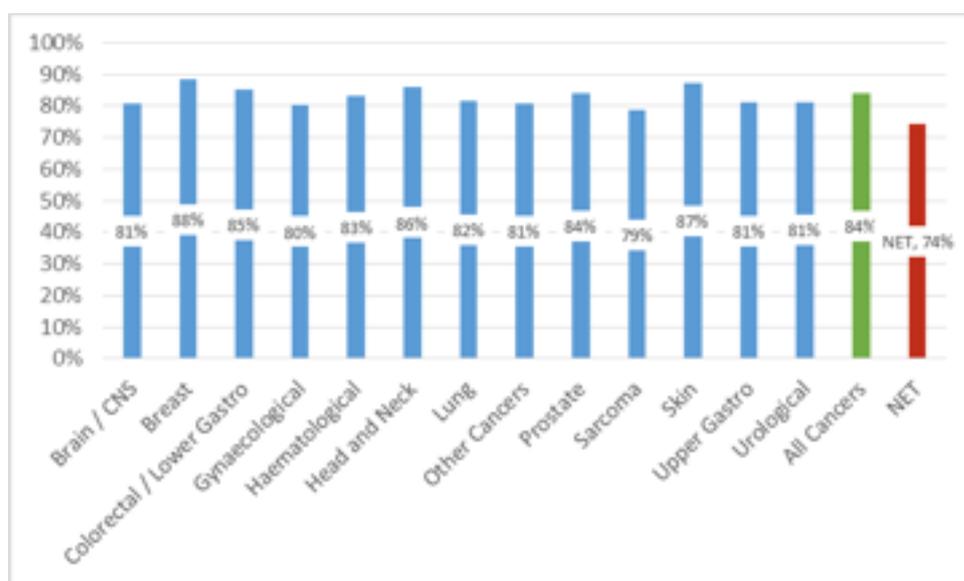


Fig.16 Proportion of patients saying there were told they had cancer sensitively

### 3.20 Understanding the explanation of what was wrong

Under a half (47%) of respondents completely understood the explanation of what was wrong (while this was 73% in the national CPES). 42% of people said that they understood some of it. While 11% said that they didn't understand the explanation of what was wrong with them.

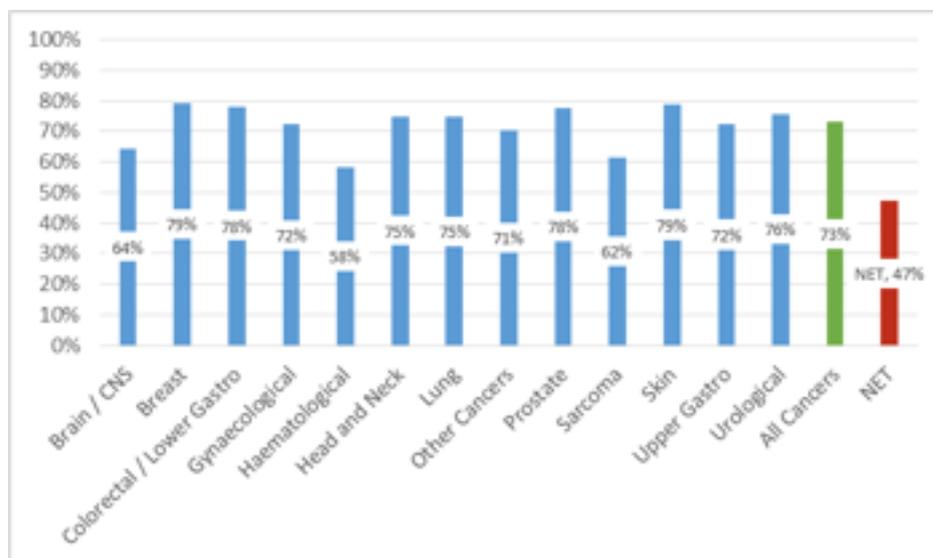


Fig.17 Proportion of patients saying they understood the explanation of what was wrong with them

### 3.21 Being given written information about their type of cancer

Of those who needed it, well over one-third (39%) of respondents said that they didn't receive any written information about their type of cancer. This was far lower in the national CPES at 20%. 14% (8% in CPES) said that they did receive written information but found it hard to understand. 47% received written information and said it was easy to understand. This was far higher in the national survey at 72%.

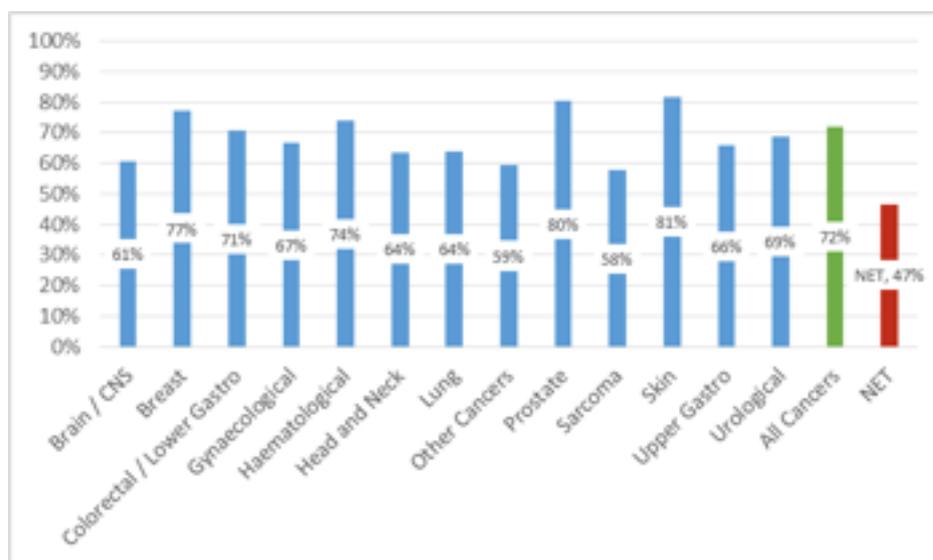


Fig.18 Proportion of patients saying they were given written information that was easy to understand

### 3.22 TREATMENT AND CARE

This section of the survey asked respondents about their treatment and care, including: how long it took for treatment to start since first seeing their GP; whether they were referred to a NET clinic; and whether or not they had a choice of treatment.

#### 3.23 How long since first treated for neuroendocrine cancer

Most respondents (57%) said that they were first treated for neuroendocrine cancer between 1 and 5 years ago. 19% said more than 5 years; and 11% said more than 10 years.

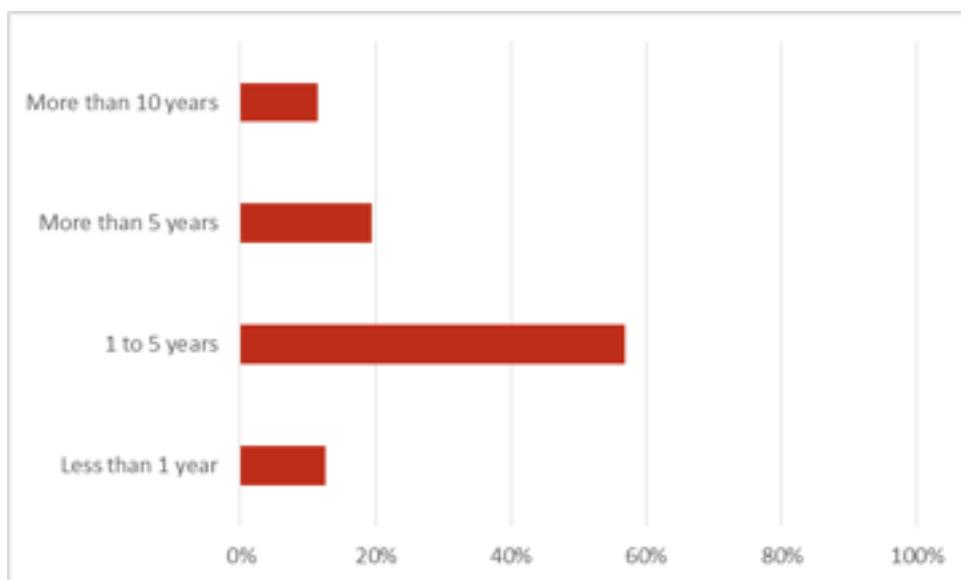


Fig.19 How long since patient was first treated for neuroendocrine cancer

### 3.24 How long since going to GP and treatment for neuroendocrine cancer started

We then asked how long it had been since first going to their GP about their condition, to being started on treatment for neuroendocrine cancer. Just under one-third (29%) said this was less than 3 months; 26% said between 3 and 6 months.

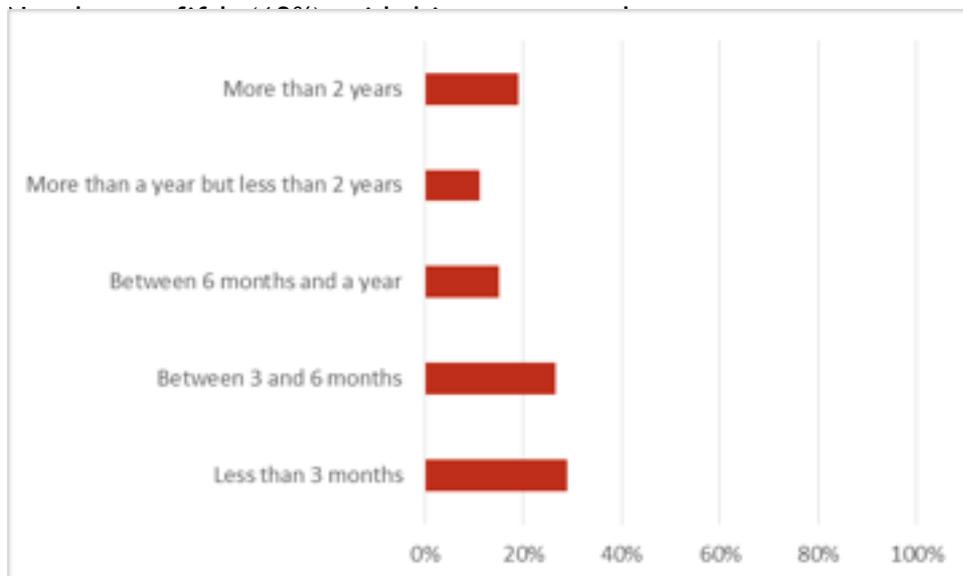


Fig.20 How long between first seeing GP and starting treatment for neuroendocrine cancer

### 3.25 Symptoms changing during first seeing GP and starting treatment

Over one-third (38%) of respondents said that their symptoms became worse in the time between first seeing their GP and starting treatment for neuroendocrine cancer. Just over half (53%) said that they stayed about the same; and for a small number (8%) symptoms improved.

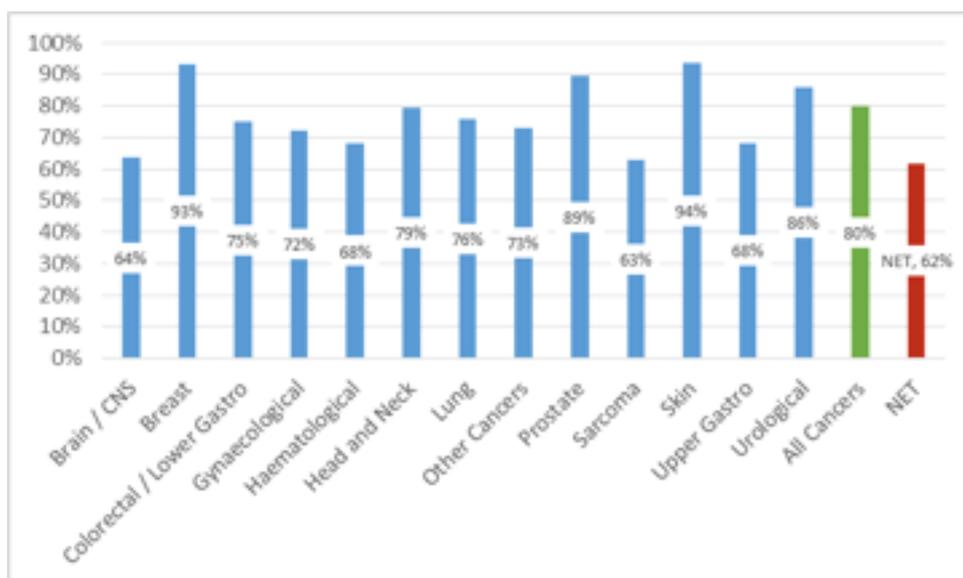


Fig.21 Proportion of patients saying their health stayed the same or got better during first seeing GP and starting treatment

### 3.26

### Being referred to a NET clinic

Nearly two-thirds (61%) of respondents were referred to a NET clinic; with over a third (39%) saying they were not referred to a NET clinic.

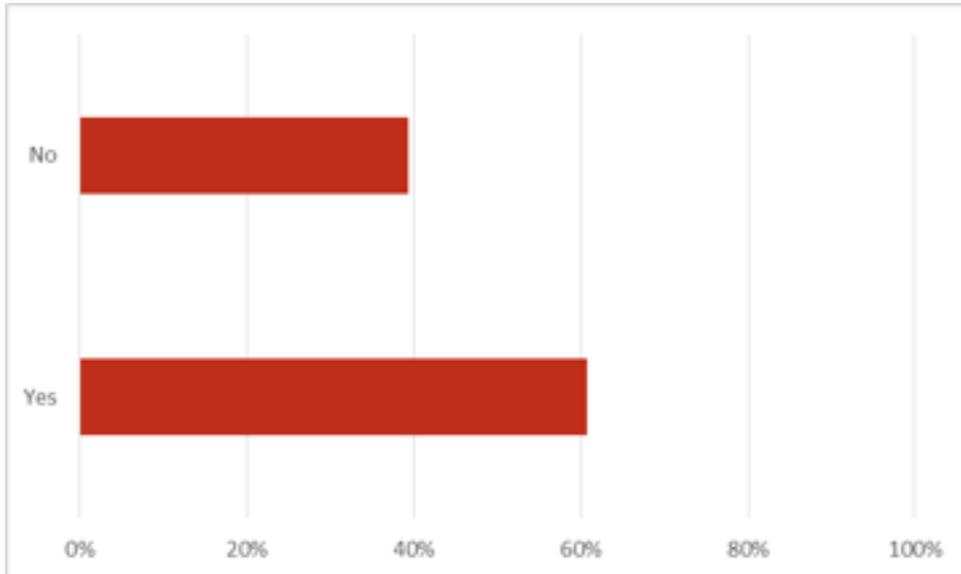


Fig.22 Proportion of patients referred to a NET clinic

### 3.27 Who referred them to a NET clinic

The majority of respondents were referred to a NET clinic by their local hospital (81%). A further 8% said their GP; and 3% referred themselves.

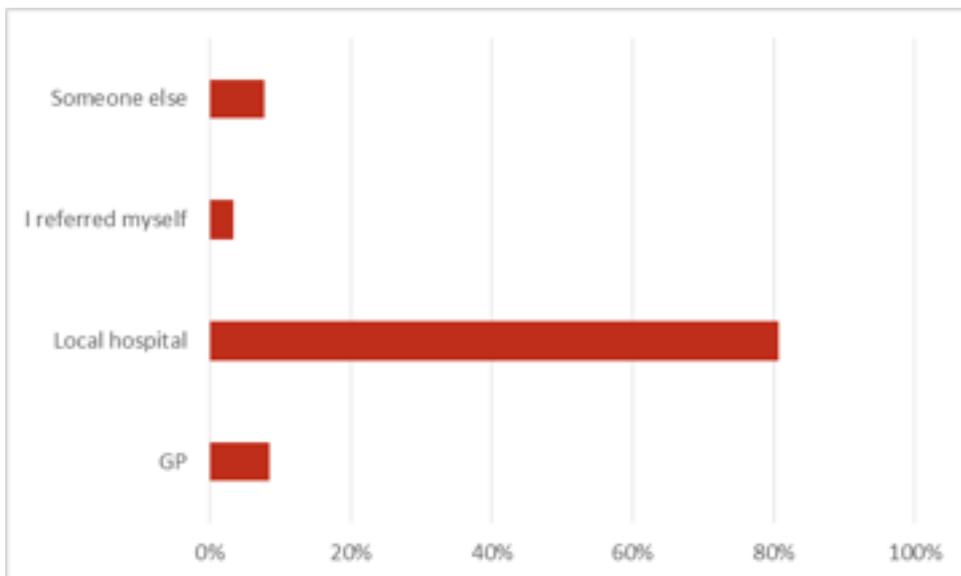


Fig.23 Who referred the patient to a NET clinic

### 3.28 Being given a choice of types of treatment

Most respondents (68%) said that they were not given a choice because there was only one type of treatment suitable for them. Of the other respondents, nearly two-thirds (61%) said that they were given a choice of treatment types before their cancer treatment started. About one-third said that they were not but would have liked a choice (39%).

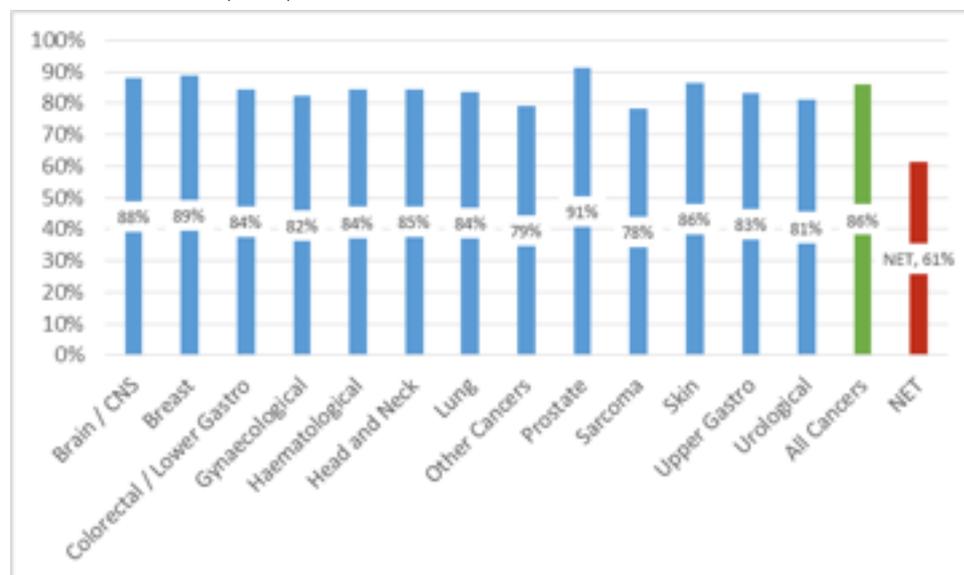


Fig.24 Proportion of patients being given a choice of treatment types

### 3.29 Views being taken into account when discussing treatment

We asked whether or not respondents thought that their views were taken into account when the team of doctors and nurses caring for them were discussing what treatment they should have. 60% said yes, this was definitely the case (in the national CPES this was 71%). 31% said yes, to some extent (compared to 23% in CPES); and 10% said their views were not taken into account (compared to 6% in CPES).

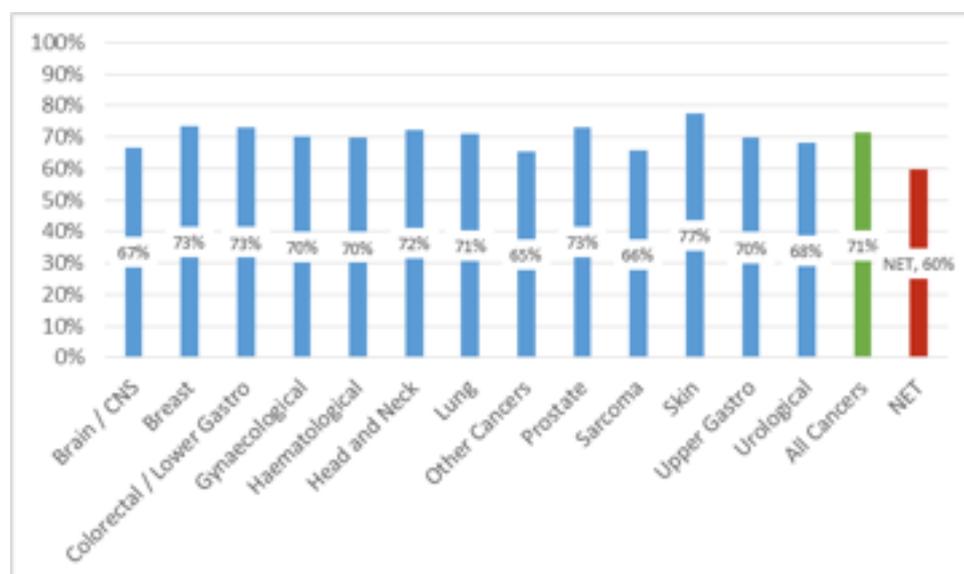


Fig.25 Proportion of patients saying they thought their views were taken into account when discussing treatment and care

### 3.30 Possible side effects of treatment

Of those who said they needed an explanation, 60% said that the possible side effects of treatment were definitely explained to them in a way they could understand (compared to 75% in the national CPES). Nearly a third (28%, compared to 21% in CPES) said yes, to some extent; and 12% said that possible side effects were not explained (compared to 4% in CPES).

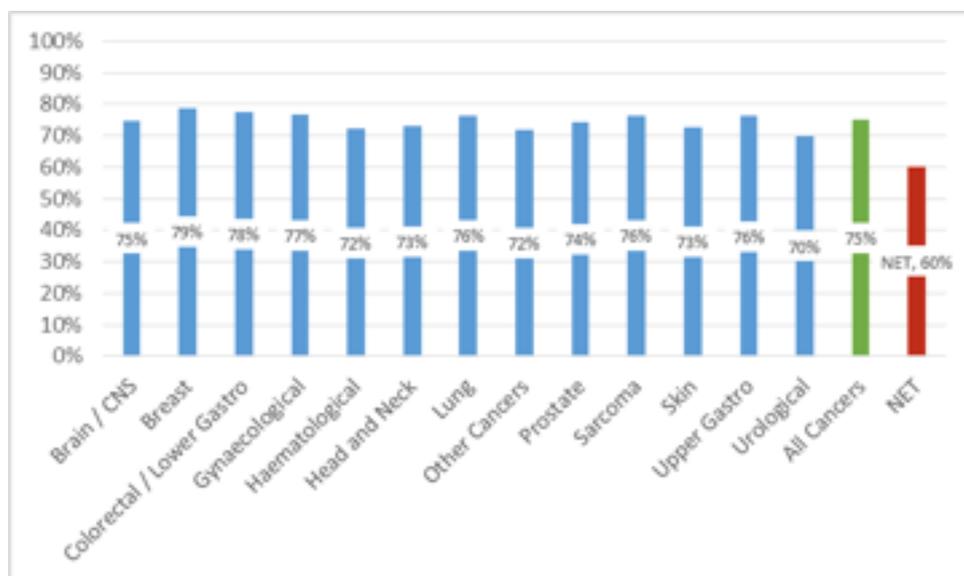


Fig.26 Proportion of patients saying side effects were explained in a way they could understand

### 3.31 Written information about side effects

Just over one-third (34%) of respondents were not given any written information about side effects of treatment (compared to 12% in the CPES). 57% received this information and said it was easy to understand (compared to 82% in the CPES); 9% who received information said it was not easy to understand (compared to 5% in the CPES).

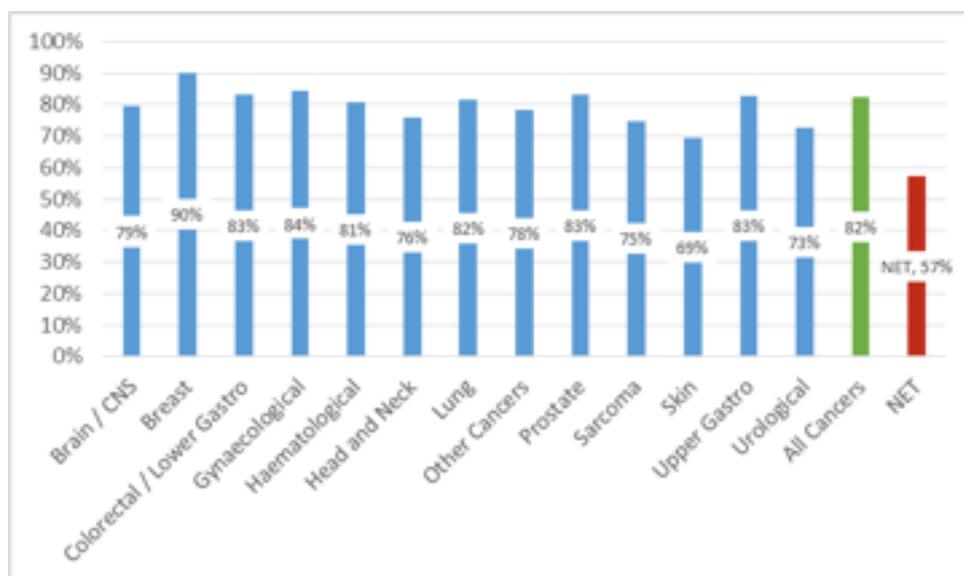


Fig.27 Proportion of patients saying they received written information about side effects which was easy to understand

### 3.32 Involved in decisions about treatment and care

We asked whether or not respondents were involved as much as they wanted to be in decisions about their treatment and care. Nearly two-thirds (63%, compared to 72% in the CPES) said yes, definitely. Just under a third (29%, compared to 23% in the CPES) said yes, to some extent. And 8% (compared to 5% in the CPES) said they would have liked to have been more involved.

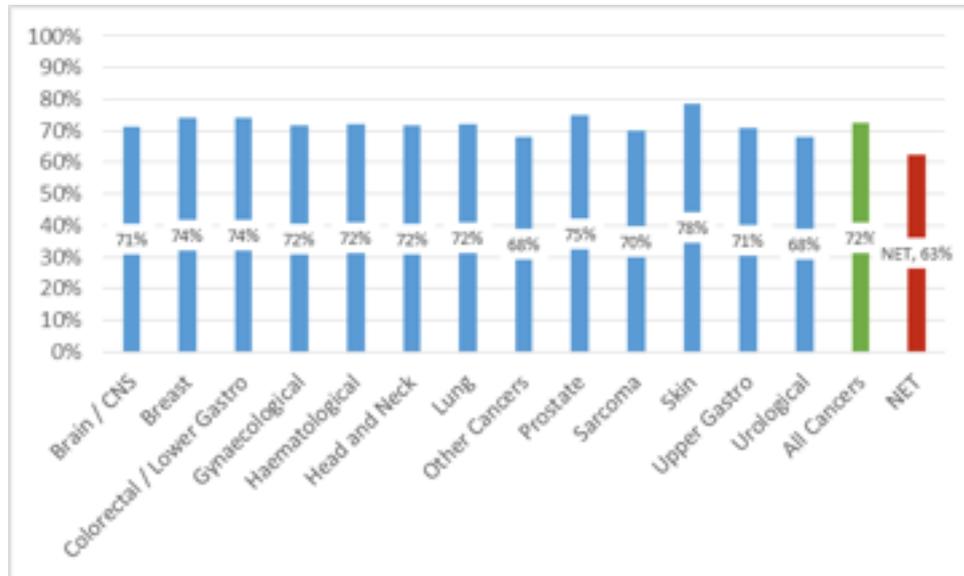


Fig.28 Proportion of patients saying they definitely felt involved in decisions about their treatment and care

### 3.33 Types of treatment

We asked respondents which treatment types they had undergone since being diagnosed with neuroendocrine cancer. Nearly two-thirds (64%) had had an operation. While half (50%) had had Octreotide or Lanreotide injections. The next most common (19%) had received radio-targeted therapy; and 18% were on 'Watch and Wait'.

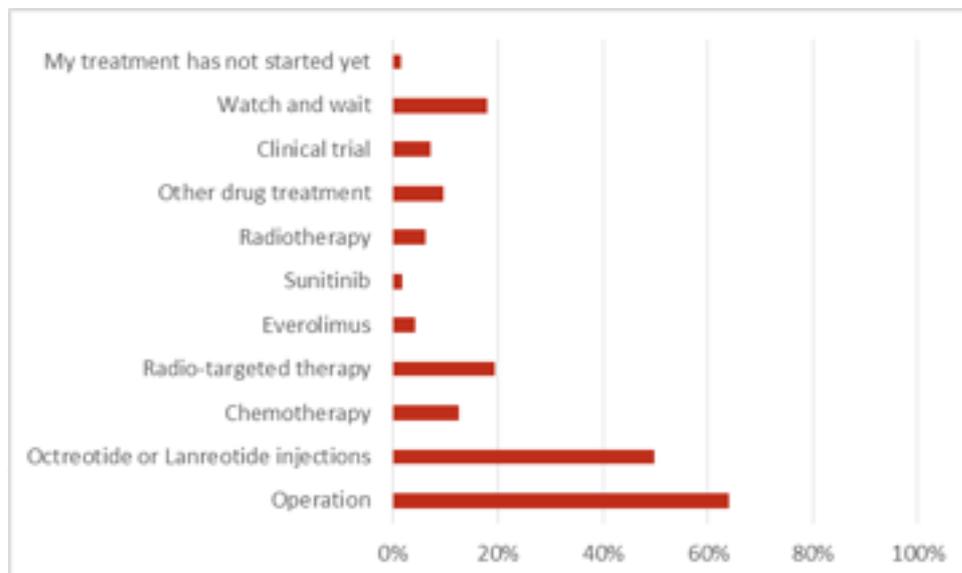


Fig.29 Types of treatment received

they had a trust in their CNS

### 3.35 Having a CNS who is a specialist in neuroendocrine cancer

Nearly three-quarters (74%) of respondents said that they had a CNS who was a specialist in neuroendocrine cancer. This compares to 89% of people responding to the national cancer patient experience survey 2014, who said that they had a clinical nurse specialist.

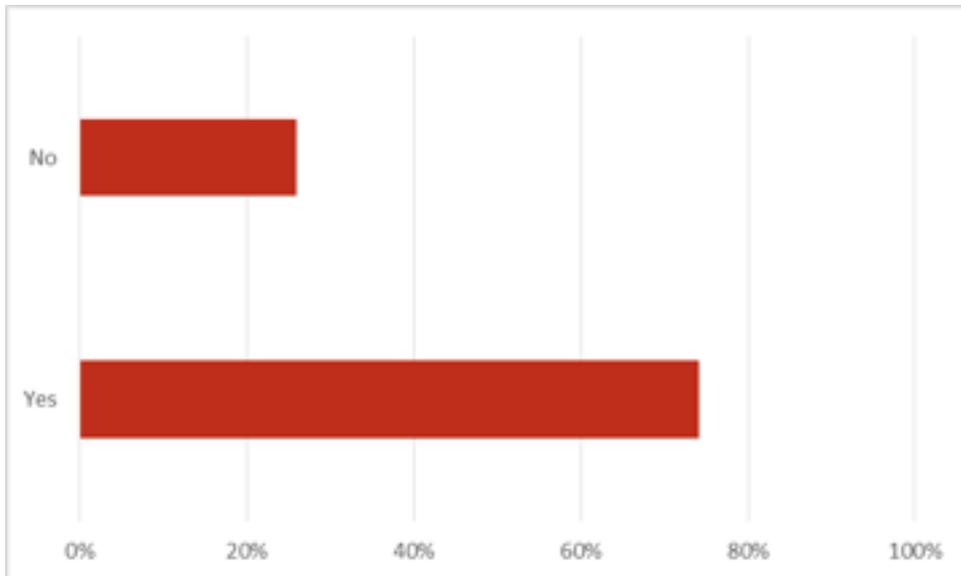


Fig.30 Proportion of patients saying they had a clinical nurse specialist who was a specialist in neuroendocrine cancer

### 3.36 Confidence and trust in their clinical nurse specialist

Nearly everyone (97%) of people who had a CNS, said that they had confidence and trust in them. 3% said they did not.

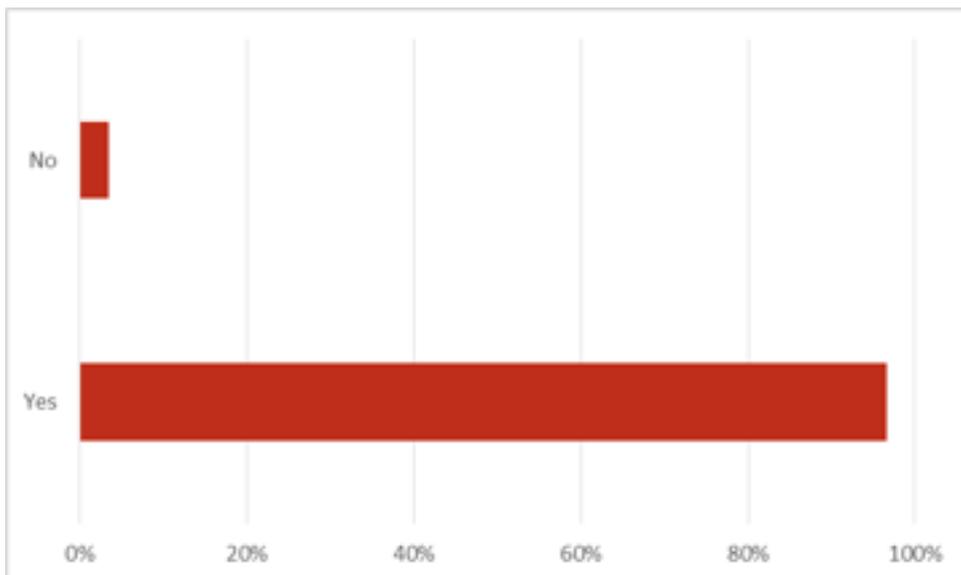


Fig.31 Proportion of patients saying they had confidence and trust in their clinical nurse specialist

### 3.37 Awareness of their cancer

Again, nearly everyone (99%) said that their CNS had good awareness of their cancer.

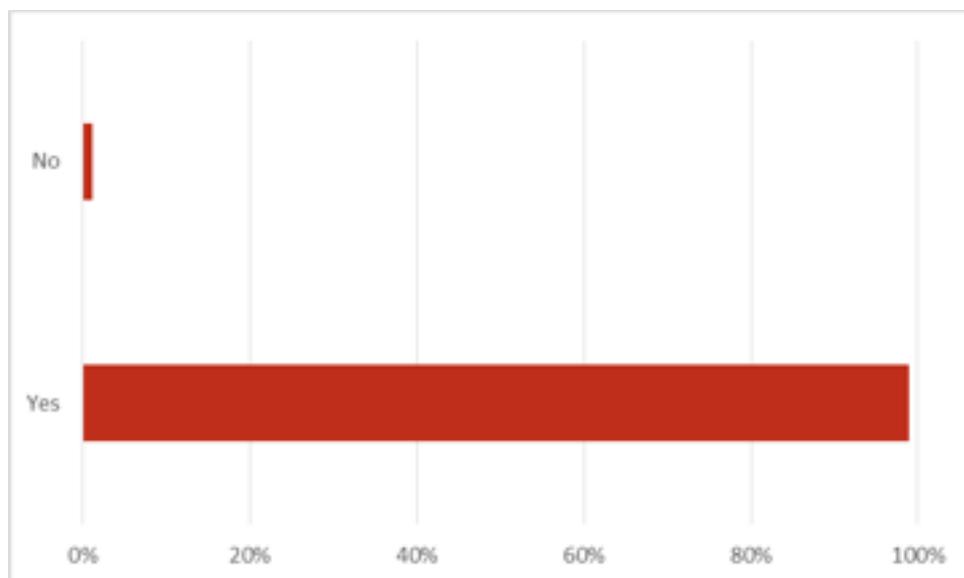


Fig.32 Proportion of patients saying their clinical nurse specialist had a good awareness of their cancer

### 3.38 Types of support offered

We asked respondents what type of support their NET clinical nurse specialist offered before, during and after treatment. 47% of respondents said explanations and answering questions; and 46% said follow up telephone calls.

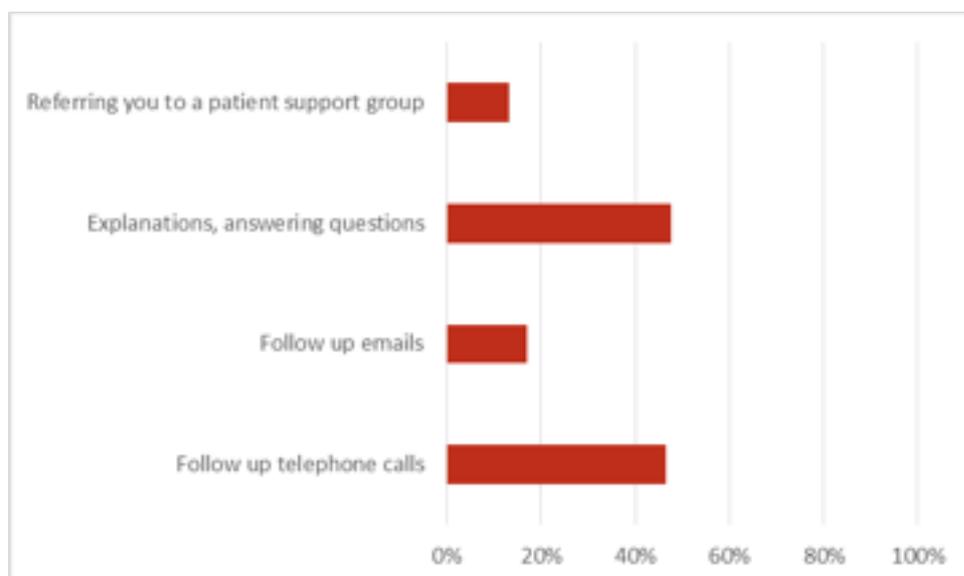


Fig.33 Type of support provided by their clinical nurse specialist

### 3.39 SUPPORT FOR PEOPLE WITH NEUROENDOCRINE CANCER

This section of the survey asked respondents about the types of support they were offered and received; and how they rated the information they received about their condition.

### 3.40 Information about support or self-help groups

We asked whether hospital staff gave respondents information about support or self-help groups for people with neuroendocrine cancer. A quarter said this was not necessary. Of the remaining respondents, 46% said they did get this information (compared to 83% in the national CPES); while 54% did not but would have liked this information (compared to 17% in the CPES).

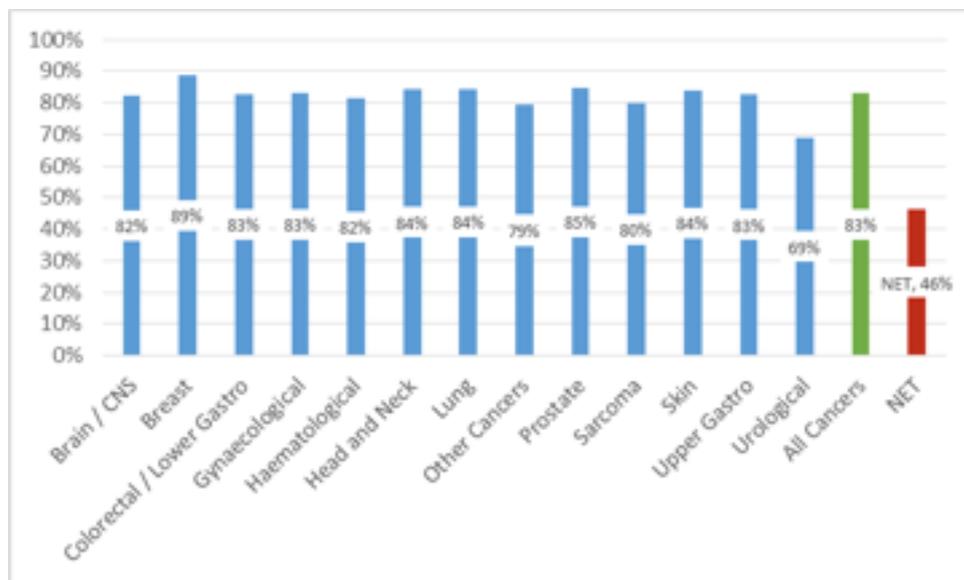


Fig.34 Proportion of patients saying they received information about support and self help groups

### 3.41 Impact of cancer on work life and education

We asked whether hospital staff discussed, or gave information on, the impact cancer could have on their work life or education. 40% of people said this was not relevant to them. Of the remaining respondents just over half (53%, compared to 25% in the CPES) said they didn't get this information but would have liked it.

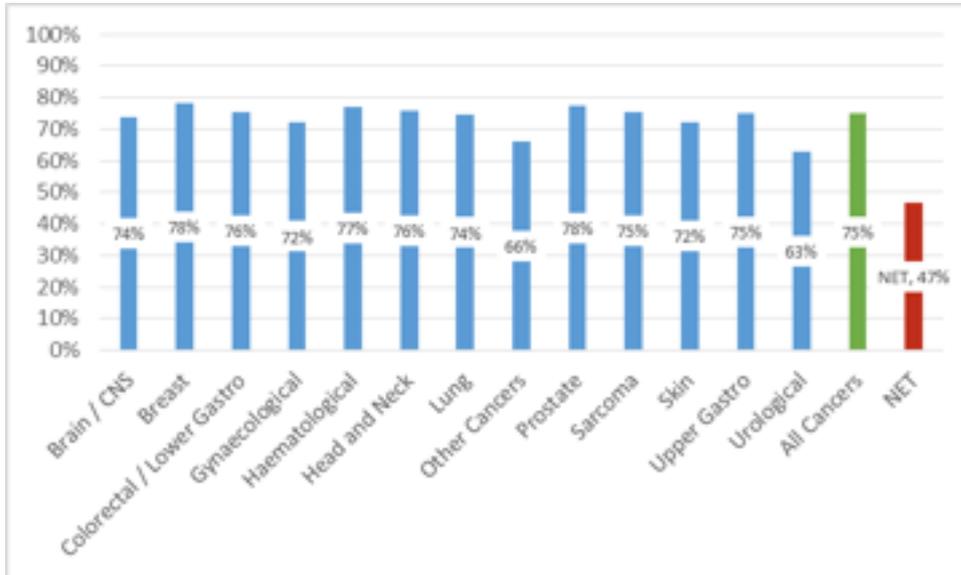


Fig.35 Proportion of patients saying they were given information about the impact that cancer would have on their work life or education

### 3.42 Information received from a cancer charity

We asked about the information respondents received from cancer charities. Over half (60%) said they did not receive any support from a cancer charity. Of those who did receive support, 12% said this was written information; and 12% said information/advice from a NET website.

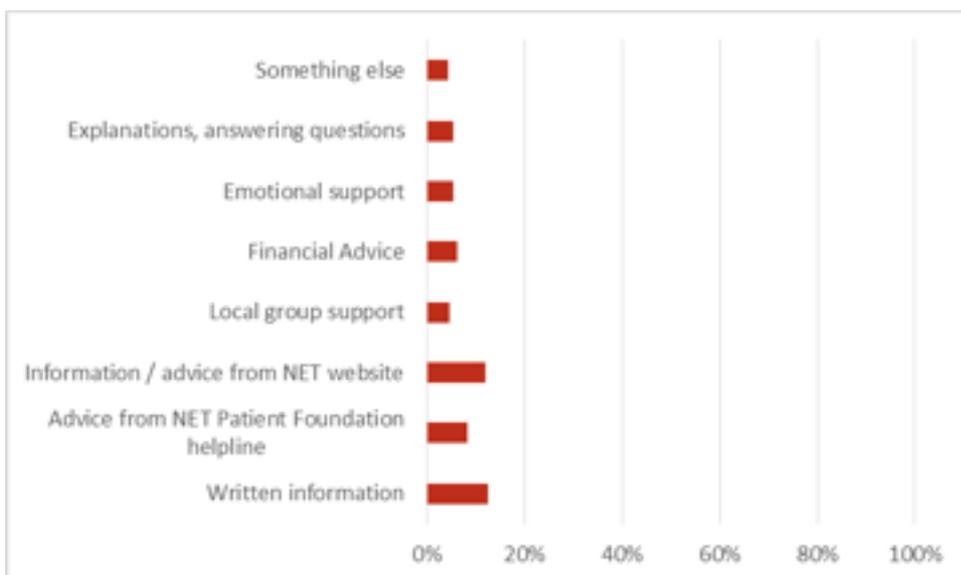


Fig.36 Types of information received from cancer charities

### 3.43 Amount of information received

Nearly one-third (29%) said that they were not given enough information about their condition and treatment. 71% said they received the right amount.

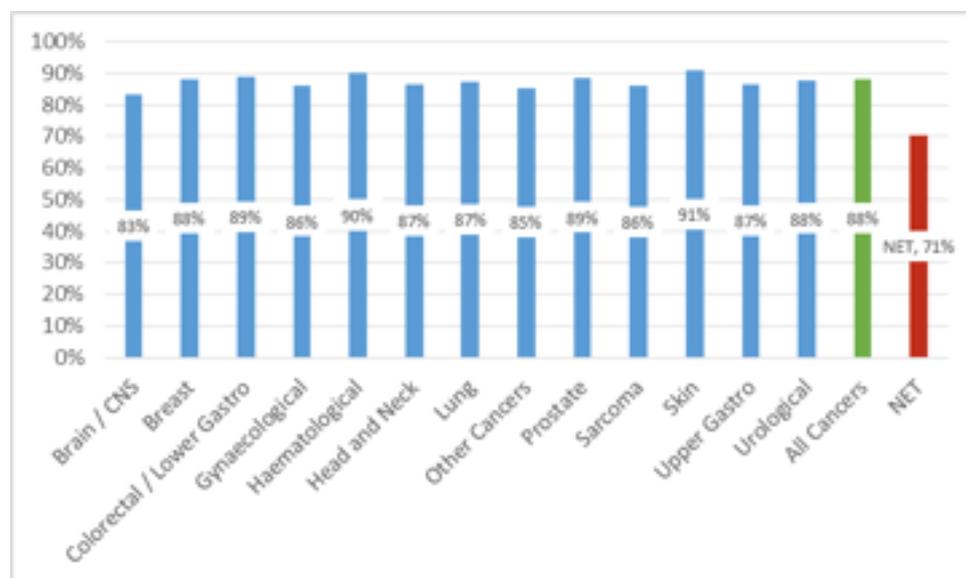


Fig.37 Proportion of patients who feel they were given just the right amount of information about their condition and treatment

### 3.44 HOSPITAL STAFF AND THEIR GP

We asked respondents about the staff they encountered at the hospital; whether they had trust and confidence in them; and whether they were given the right level of support.

### 3.45 Confidence and trust in hospital staff

Three-quarters of respondents said they had confidence and trust in all of the hospital staff treating them. One-quarter said only some of them.

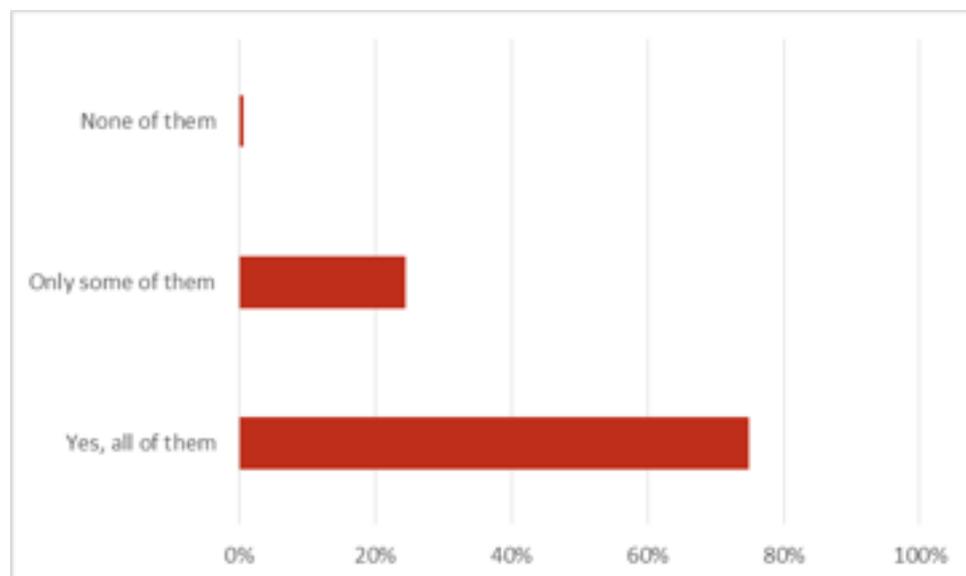


Fig.38 Proportion of patients saying they had confidence and trust in the hospital staff treating them

Three-quarters (65%) said that they thought that all of the hospital staff treating them had a good awareness of their neuroendocrine cancer. 32% said only some of them did. 3% said none of them.

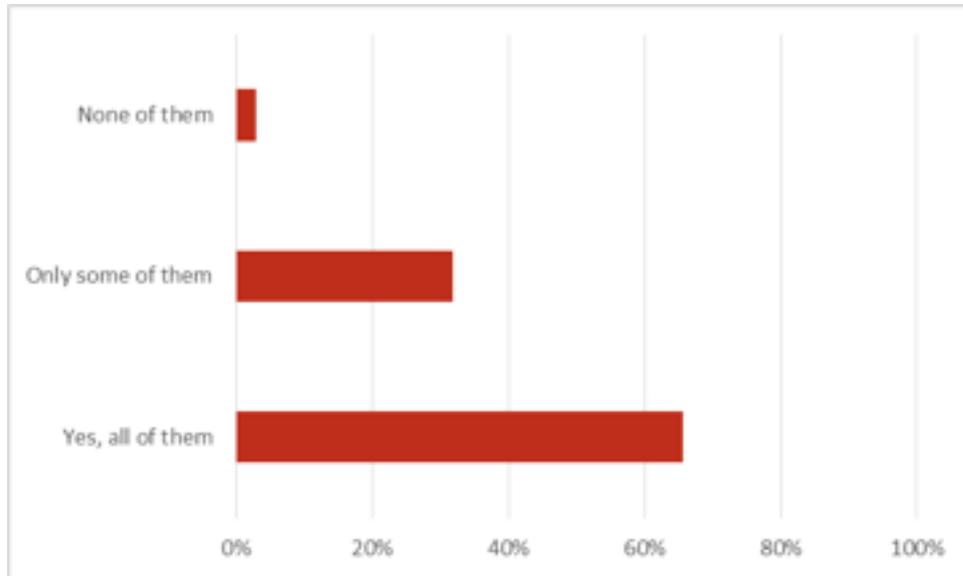


Fig.39 Proportion of patients saying staff had good awareness of their neuroendocrine

### 3.47 Emotional support

We asked whether respondents who were being treated as an outpatient or day case were given enough emotional support from the hospital staff. A half (50%) said yes, definitely. 36% said yes to some extent; and 14% said that they would have liked more support.

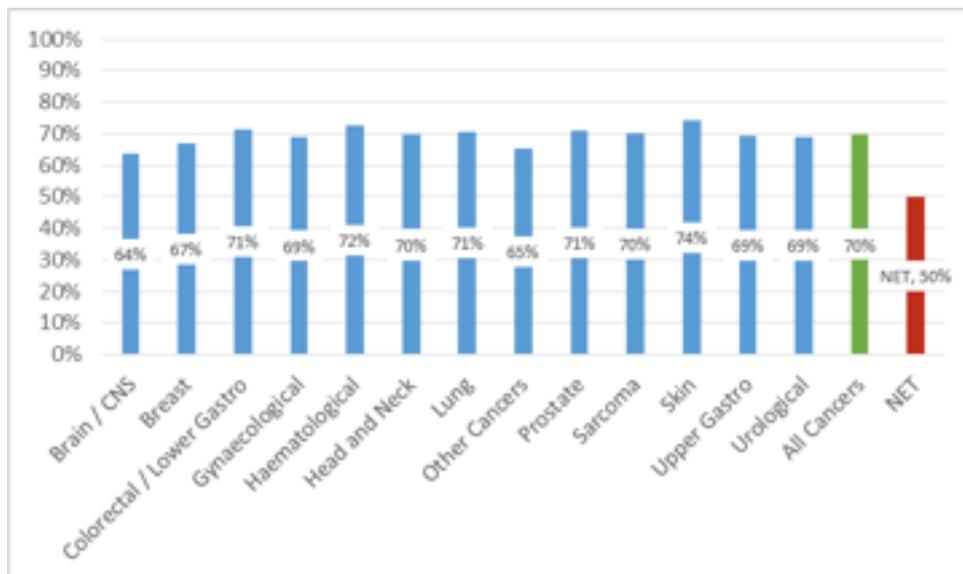


Fig.40 Proportion of patients saying they were given enough emotional support

### 3.48 GP having enough information about treatment at hospital

Most respondents (86%, compared to 95% in the national CPES) said that their GP had enough information about their condition and the treatment that they'd had at hospital. 14% said no to this, compared to 5% in the national CPES.

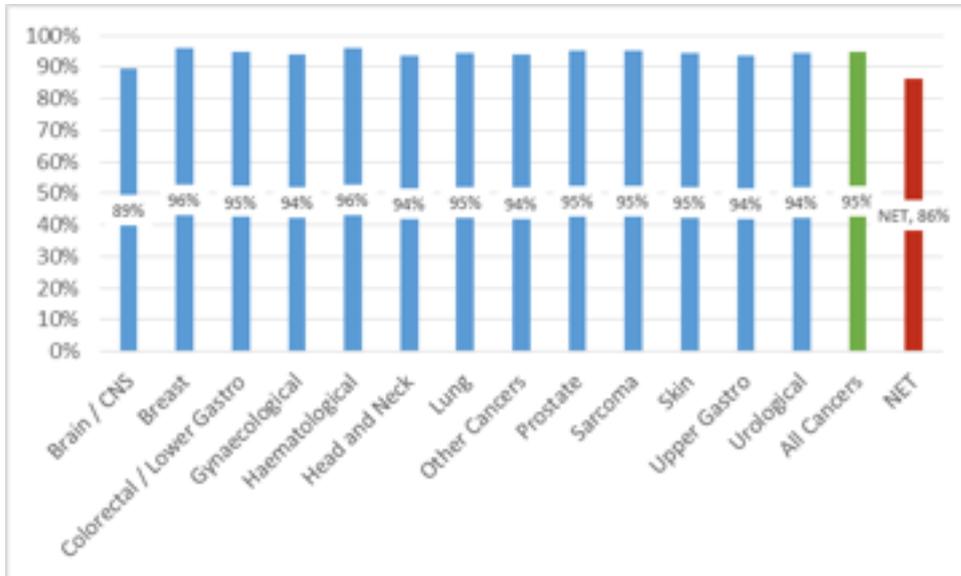


Fig.41 Proportion of patients saying their GP had enough information about their treatment and care in hospital

### 3.49 GP having a good understanding of neuroendocrine cancer

43% said that their GP had a complete understanding of their neuroendocrine cancer. A further 42% said only some understanding; while 15% said no.

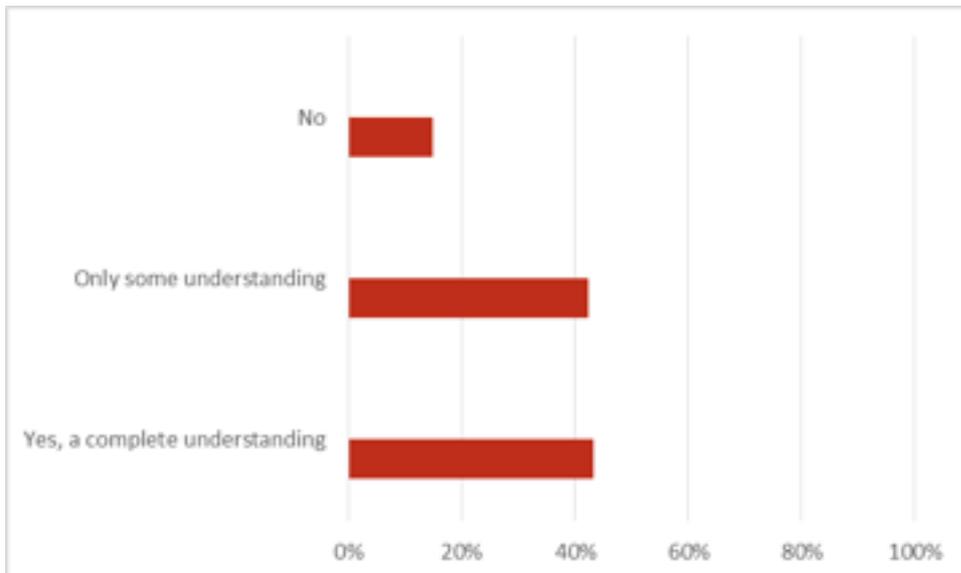


Fig.42 Proportion of patients saying their GP had a complete understanding of their neuroendocrine cancer

### 3.50 Support from GP and nurses at general practice

Just over a half of respondents (54%, compared to 66% in the national CPES) said that their GP and staff at the general practice definitely did everything they could to support them while having their cancer treatment. 31% said yes, to some extent (23% in the CPES), and 15% said no, they could have done more (compared to 11% in the CPES).

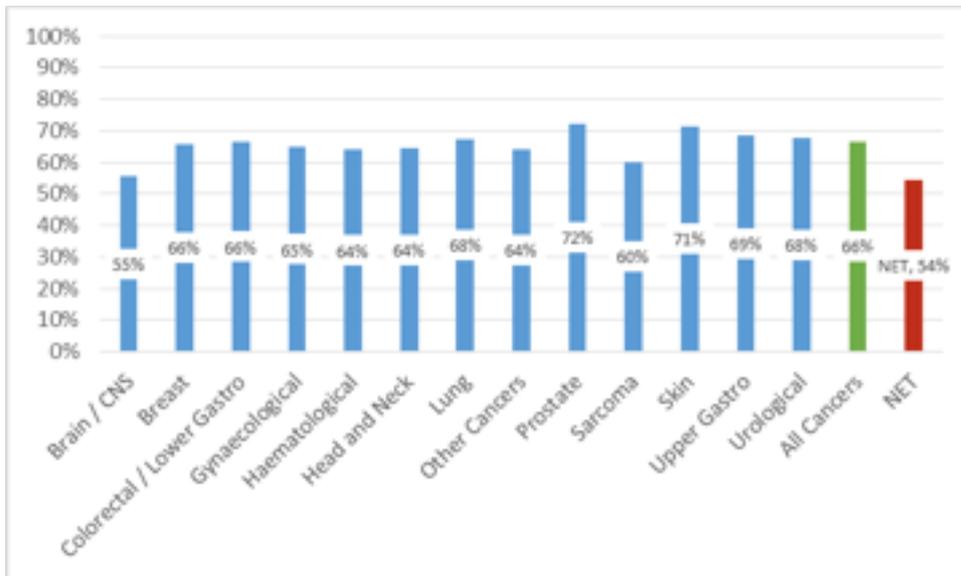


Fig.43 Proportion of patients saying their GP and staff at their general practice did everything they could to support them while having cancer treatment

### 3.51 OVERALL NHS CARE

We asked respondents to think about their care overall, including how well the different people caring for them worked together; and how they would rate their NHS care overall.

### 3.52 People caring for you working well together

Under a half (42%) said that the people caring for them (e.g. GP, hospital doctors, hospital nurses, specialist nurses, community nurses) worked well together to give the best care possible - this compared to 63% in the CPES. 37% said yes, most of the time (27% in the CPES); and a further 16% said yes, some of the time (8% in the CPES). 5% said no, never (2% in the CPES).

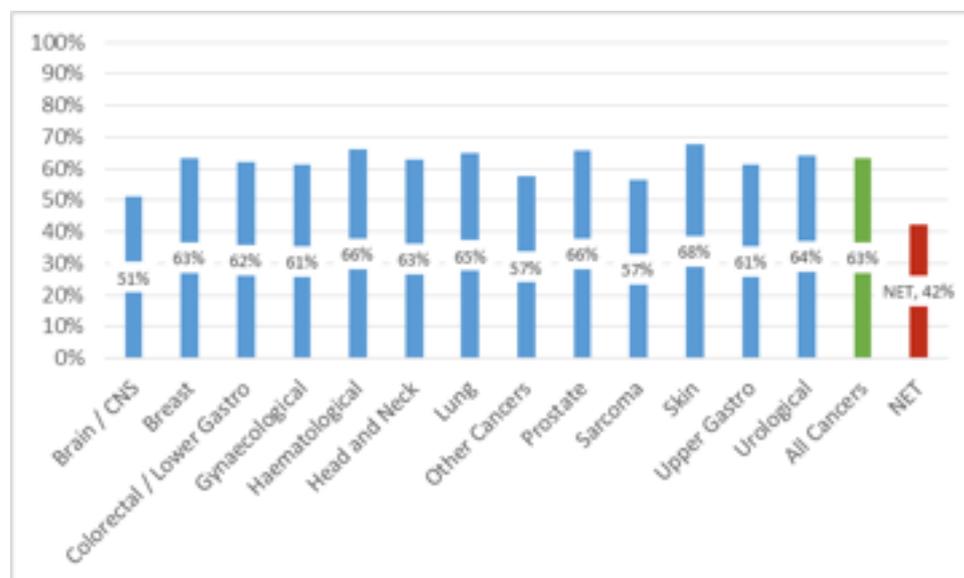


Fig.44 Proportion of patients saying the people caring for them worked well together to give them the best possible care

### 3.53 Treated as a set of cancer symptoms

Sometimes people with cancer say they feel they are treated as a set of cancer symptoms, rather than a whole person. We asked respondents if they felt like this in the last year of their NHS care. Over two-thirds (67%) said no, never (this compared to 81% in the CPES). While a quarter (25%) said yes, sometimes (15% in the CPES); and 8% said yes, often (3% in the CPES).

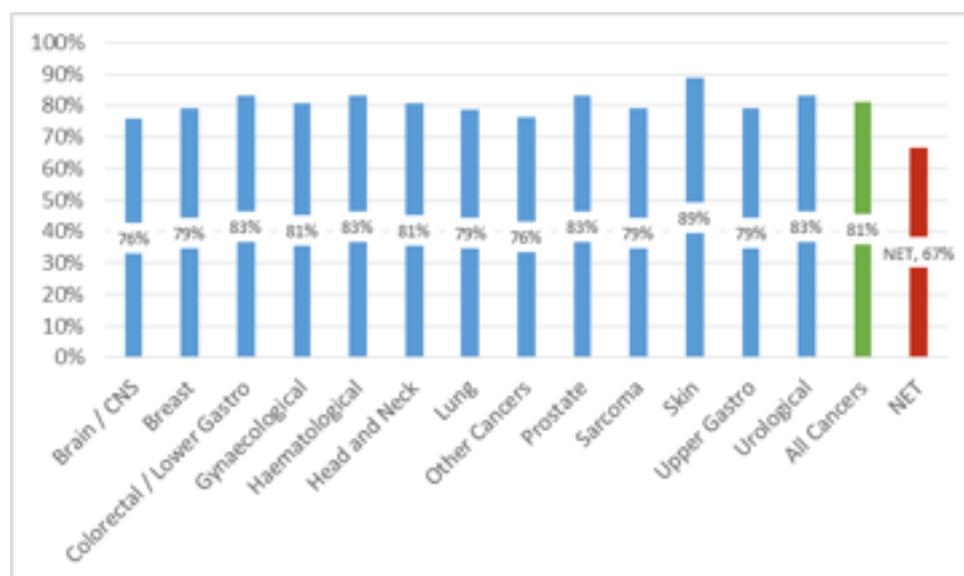


Fig.45 Proportion of patients saying they did not feel that they were treated like a set of cancer symptoms rather than a whole person

### 3.54 Overall rating of care

Nearly a half of respondents (47%) rated their care as excellent (compared to 57% in the CPES). 36% said very good (compared to 32% in the CPES). And 12% good. Just 1% said poor. So, 83% of respondents rated their care as excellent or very good; compared to 89% in the national cancer patient experience survey.

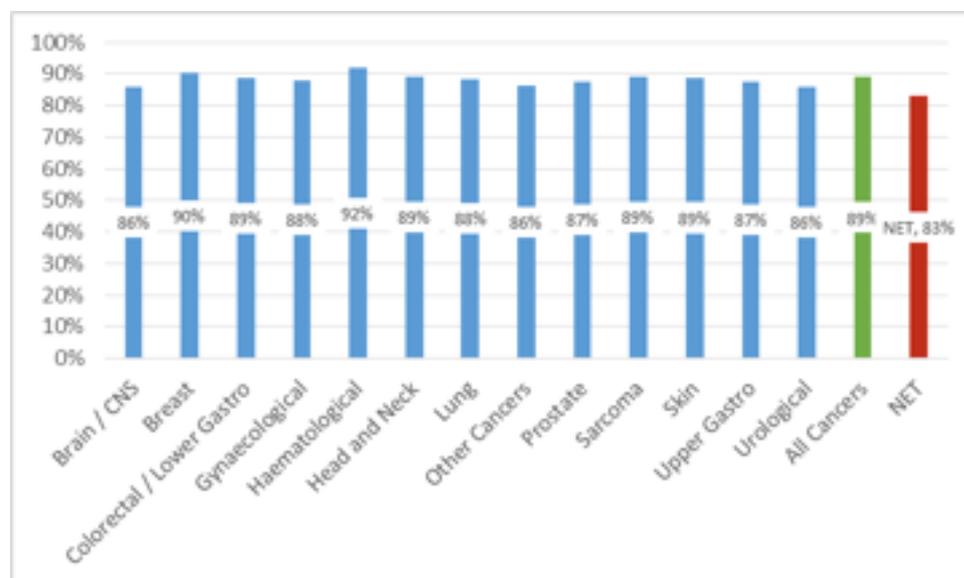


Fig.46 Proportion of patients rating their care as excellent or good

## 4. Written comments analysis

This section of the report presents a thematic analysis of the Net Patient Foundation Cancer Patient Experience Survey free text comments received from NET cancer patients who returned a questionnaire.

At the end of the survey, respondents were invited to record any further comments that they wished to make. This report presents a thematic analysis of those comments.

### 4.1 Thematic analysis

In order for Net Patient Foundation to understand and identify the main issues contained within the comments, Quality Health carried out a systematic analysis of the comments by theme.

Every comment has been typed up by Quality Health staff, and 'sanitised' (removing any patient identifiable data, and removing any staff names or details). Net Patient Foundation has also been given a 'raw data' file containing all of these comments.

During this process, Quality Health categorised the comments in two ways:

1. By the nature of the comment, i.e. whether it is positive, negative or neutral
2. By the theme which it addresses. The themes arising from the comments are listed below in order of the highest number of comments, to lowest:

- Treatment & Care
- Diagnosis
- Specialist NET clinics
- GPs
- Feeling fully informed about care and treatment / lack of information
- Thank you/feeling positive
- Clinical Nurse Specialist
- Side effects / long term effects and consequences
- Extra support/support groups
- Health Status
- After Care
- Net Patient Foundation

Within each of these categories, Quality Health has identified comments as positive, negative, or neutral.

A summary of the overall responses is provided in the next section of this report. The more detailed section that follows reports on each theme individually, and provides examples of actual comments against each.

## **4.2 Summary Results**

There were 514 comments received in total.

The themes covered by the comments are shown below and the numbers of comments recorded in that theme. Some comments relate to more than one theme, and so these have been recorded more than once. Therefore, the numbers of comments adds up to more than 514.

The themes with the highest proportion of positive comments are:

- Thankful / feeling positive (100% positive comments)
- Net Patient Foundation (100% positive comments)
- Specialist Net Clinics (87% positive comments)
- Clinical Nurse Specialists (70% positive comments)

The themes with the highest number of negative comments are:

- Feeling fully informed about their cancer and their care (94% negative comments)
- Side effects of having cancer/side effects of treatment (89% negative comments)
- General Practitioners (84% negative comments)
- Diagnosis - including time taken to get one (82% negative comments)

The table on the following page breaks down each comment theme and shows the total number of comments broken down by positive, negative and neutral.

### 4.3 Table of Summary Results

THEME	Positive Comments	%	Negative Comments	%	Neutral Comments	%	TOTAL COMMENTS
Treatment & Care	138	45	100	32	71	23	309
Diagnosis	5	4	93	82	16	14	113
Specialist NET clinics	90	87	7	7	6	6	103
GPs	14	15	78	84	1	1	93
Feeling fully informed about care and treatment / lack of information	4	6	61	94	0	0	65
Thank you/ feeling positive	52	100	0	0	0	0	52
Clinical Nurse Specialist	14	70	6	30	0	0	20
Side effects / long term effects and consequences	0	0	17	89	2	11	19
Extra support/ support groups	3	18	14	82	0	0	17
Health Status	7	44	8	50	1	6	16
After Care	6	40	9	60	0	0	15
Net Patient Foundation	4	100	0	0	0	0	4

## 4.4 Results by Theme

### 4.4.1 Treatment and Care

The most common comment throughout this survey - perhaps unsurprisingly - related to treatment and care for NET cancer with a total of 309 comments being made.

These comments included details on treatment which respondents were undergoing, or side effects, or consequences of treatment that they were experiencing.

138 (45%) of these comments were positive; 100 (32%) were negative; and 71 (23%) were neutral. There was a real spread of responses with some reporting vastly different experiences, from excellent treatment and care, to extremely poor treatment and care.

Where comments for treatment and care referred to a specialist NET clinic they were overwhelmingly positive. In most other cases, the comment was negative as hospitals failed to treat the condition effectively.

Some examples of positive comments are:

*“The treatment and care I received for my neuroendocrine tumour and the subsequent cystectomy [date removed] were excellent. I hope the NHS continues its excellent and most civilised service.”*

*“I would like to thank all the doctors, nurses and every other person who has cared and treated me over the years. I would especially like to thank the surgical team of [name removed] for their care and consideration, especially [name removed] himself at The Royal Free Hospital. Finally, I would like to thank [name removed] and his team for their wonderful advice, care and support.”*

*“My treatment was excellent. Lovely, clever doctor!”*

Some examples of negative comments are:

*“Very poor communication between the various professionals. Little or no contact and when contact is made, information is at best sketchy. Get a NET and you are on your own, that’s what it feels like. Yes it is rare I get that, but we are still people living with cancer and in my experience I have been ignored and marginalised.”*

*“At local hospital level there seems to be a lack of knowledge with regards to this type of cancer. Initial contact with NHS oncologists at local level revealed that their procedures, post diagnosis, were at odds with those experts at The Christie.”*

*“Individual doctors and nurses were very good. Let down by hospital administration, delayed test results, delayed appointments, operations and letters etc. I felt that I had to push to get good care.”*

#### 4.4.2 Diagnosis

Comments discussing diagnosis of participants' NET cancers was overwhelmingly negative. Just 5 (4%) of these comments were positive; 93 (82%) were negative; and 16 (14%) were neutral. In almost all cases, diagnosis took far longer than respondents thought was acceptable. Again, in almost all cases this was due to a lack of understanding about NET cancers and a lack of knowledge specifically with GP.

Almost all comments were negative and included:

*"Before my cancer was diagnosed through surgery for small bowel blockage, I was told by hospital doctor that there was nothing wrong and to go away and live my life. After [number removed] years of treatment I have now had to have small bowel bypass and have lost most of my small bowel and part of my colon. I also have a colostomy."*

*"Very disappointed that it took [number removed] years to diagnose my NET. I am very pleased with the treatment at the Royal Liverpool Hospital and the operation at Aintree Hospital."*

*"I believe my symptoms were ignored for a long time due to my age - even though my [family member removed] had same tumour."*

*"I was misdiagnosed for approximately [number removed] years on NHS. Cancer was discovered when my GP referred me for an ultrasound. They asked me if I had private cover because now was the time I needed to use it. I have had a mix of NHS and private care."*

#### 4.4.3 Specialist NET clinics

A total of 103 comments were made in relation to specialist NET clinics. The main problem was access to these clinics, with many respondents commenting that they had to fight for referrals. When patients were finally treated by a specialist NET clinic, or had them overseeing their care, the comments were overwhelmingly positive.

For those who were treated at a NET clinic or who had their treatment managed by one, 90 (87%) of these comments were positive; 7 (7%) were negative; and 6 (6%) were neutral.

There were many positive comments including:

*"The NET specialist centre (Christie) was fantastic and took the best possible care of me from first day I saw them. I cannot thank [name removed] enough and my surgeon [name removed] enough and they continue to give me the best possible care I could ever ask or pay for (I am NHS). But - my local hospital were awful, they refused me treatment, informed me of my inoperable and untreatable cancer over the phone. There was no follow up care and I was left to die alone. They refused to refer me to NET centre if I had not known people in the PCT and also self referred myself to Christies, I would probably now be dead or dying alone. I would be happy to discuss my care with anyone."*

*"The treatment and care I have received at King's College, Denmark Hill is beyond excellent. I feel that I am part of an expert and well functioning team with the same goal - to make my life as normal as possible and to give me access to the best possible treatment. I'm treated like a thinking, feeling human being, am able to discuss anything with the consultant and know they have my best interests."*

*"[Name removed] and his team at The Royal Free are the best. They remain at the forefront of NET research and the application of effective treatments. I have implicit faith in the team; have always been fully informed about what they knew, but more importantly when they do not know - what they are doing about it."*

There were relatively few negative comments, a typical example is:

*“The NET clinic in London is now difficult for me to attend. Are there no other centres outside London for these NETs? I am now being treated at my local surgery and hospital, but these NETs do not seem familiar with many NHS staff and they often have not heard of them.”*

#### **4.4.4 GPs**

Comments relating to General Practitioners were overwhelmingly negative. In almost all cases this was due to a lack of knowledge rather than a lack of care. However, almost all respondents commented on how disappointed they were with their GPs, suggesting this had damaged their overall treatment and care as it took so long to reach a diagnosis.

Just 14 (15%) of comments about GPs were positive; 78 (84%) were negative; and 1 (1%) was neutral.

Negative comments included:

*“After years of going to my GP and being given painkillers, it wasn't until I went to local A&E where I collapsed, that investigations really started.”*

*“The first [number removed] years of being unwell were a constant battle/struggle. I was constantly rejected by all GPs, hospitals, specialists, even diagnosed as [condition removed] and then even after an operation (lung) I was “cured” and eventually found a NET clinic at hospital which is helpful beyond words. NHS - 99% of it - is horrific.”*

*“GP local practice told me to go away and not come back with the same symptoms.”*

*“Like far too many people with neuroendocrine tumours, my collection of symptoms was not recognised by my GP. However, once referred to King's College and given my diagnosis, I have been very lucky in dealing with a team of highly qualified and knowledgeable professionals who have always treated me as an individual.”*

Some examples of positive comments are:

*“I have been fortunate. I had a lump on my neck and went to [country removed] on holiday. Whilst there I saw a [job title removed], she told me to see my GP in England as soon as possible. He arranged an appointment at the Churchill in Oxford.”*

*“GP, surgery staff, medical and non medical are fantastic too.”*

#### **4.4.5 Feeling fully informed about care and treatment / lack of information**

Just 4 people (6% of respondents) commented positively about feeling fully informed. The rest (94% of respondents) commented negatively when it came to receiving information.

Many of the negative comments talk about the lack of knowledge and information across many health professionals including GPs and hospital doctors. Most respondents just felt they weren't given enough information about the cancer or the treatment options. Some respondents commented that they weren't even told it was cancer. Some of the negative comments talk about treatment that they have received but now doubt was right one for them, and some respondents say they made decisions in a rush without being fully informed. For most, a lack of information at the beginning of treatment is an issue.

Some examples of negative comments are:

*“I have felt a bit confused at times as who was in charge of leading my care. It would be good to have a contact point who is in contact with surgeons etc.”*

*“I have never been asked if I would like to ask any questions and information. Sometimes I feel that I have been forgotten by the hospital staff.”*

*“During my diagnosis and subsequent treatment it has become apparent that there is a great difference in understanding regarding NET’s and the treatment options available between various staff within hospitals and between different hospitals as well.”*

*“To date, I have not been told officially that I have NET cancer. My endocrinologist mentioned that I had a low grade cancer. We are awaiting my results.”*

Of the very few positive comments, it related to having prior knowledge:

*“I am married to a doctor, so found it easier to understand the cancer.”*

#### **4.4.6 Thank you/feeling positive**

There were a significant number of respondents who used the comments section to specifically say ‘thank you’ to specific doctors or nurses or to praise their healthcare team or the NHS more widely. In addition, they expressed gratitude for their current state of health. In total, 52 people did this, and, unsurprisingly, all the comments were positive.

Some examples of positive comments are:

*“You can probably tell from my answers, but I would like to confirm that I felt I was (and still am) very well looked after. It was a horrible thing to go through, but all of the NHS staff made me feel safe and important to them. The care and sensitivity I received from them was exemplary.”*

*“I received first class treatment.”*

*“Just a very big thank you for saving my life!”*

#### **4.4.7 Clinical Nurse Specialist**

There was a positive response in the comments for those that did get to see a CNS, however many had significant problems finding one in their area, or being offered the support that they thought was on offer.

There was a not insignificant amount of negative comments around the Clinical Nurse Specialists which almost all surrounded patients not being responded to when they contacted their CNS for information.

Some examples of positive comments are:

*“My specialist nurse ([name removed]) has been brilliant, always available to sort out any queries or concerns. Dr [name removed] and their dedicated team were amazing in attempting the SIRT treatment and then the embolisation. So dedicated!”*

*“Treatment received/discussed with the NET nurse was very good.”*

An example of the negative comments is:

*“The specialist nurses do not keep in touch very well. They don't return calls when you want them. They should be there to help you. I do not find that is done well.”*

#### **4.4.8 Side effects / long term effects and consequences**

19 people made comments about the side effects or long term effects and consequences they were experiencing. There were no positive comments about the side effects of having a NET cancer, 17 were negative and 2 were neutral. Most of the negative comments mention problems with bowels and bowel movements after surgery.

Some examples of these negative comments are:

*“The side effects of the operation were not explained to me. After a month I had a clinic appointment and explained I was suffering from diarrhoea and incontinence. I was told this was normal and would clear up in six months - it didn't... I am still suffering, no time was this told to me as a possibility.”*

*“As a result from the operation I have suffered acute diarrhoea nearly every day for nearly [number removed] years - why? Was it because the surgeon removed my gallbladder? Why did he remove my gallbladder? Why was I not informed of the consequence of this action?”*

*“Personal difficulties encountered, such as loose stools which results in incontinence at times, I find restricting as regards movement in everyday life, also embarrassing and devaluing.”*

#### **4.4.9 Extra support/support groups**

There were 17 comments made about needing extra support or about support groups specifically. Just 3 were positive and 14 were negative. The survey respondents talked about the extra support for people with NET cancer just not being there.

The majority of comments about needing extra support were negative and included:

*“I felt very lonely when I was informed of my illness. In fact, I still feel this way. I often think that it would be of benefit to mix with other cancer patients. I have never been offered this support.”*

*“Did not feel there was enough emotional support. I was very down at one point and was just given a book to read. I was referred for therapy and was waiting so long, that I left it in the end.”*

*“The main thing was not enough support after losing significant part of lung to neuroendocrine tumour. It was very emotional. It should be part of treatment (compulsory).”*

An example of a positive comment is:

*“I have a specialist insulinoma support group available to me, which helps. I do feel NET patient does concentrate on carcinoid rather than/or inclusive for all neuroendocrine cancers.”*

#### **4.4.10 Health Status**

There were 16 comments which were specifically categorised under ‘health status’ meaning the respondent specifically commented on their current state of health. There were many more comments which could technically be categorised under health status but were primarily categorised under ‘treatment and care’. Of the 16 comments, 7 were positive, 8 were negative and 1 was neutral.

Some examples of positive comments are:

*“I am being reviewed every six months at Royal Free Hospital, Hampstead. I have not started on any treatments as yet. My symptoms are totally stable. Getting an excellent care, consultation and support at the NET clinic at Royal Free hospital, Hampstead, London.”*

*“I am being reviewed every six months at Royal Free Hospital, Hampstead. I have not started on any treatments as yet. My symptoms are totally stable. Getting an excellent care, consultation and support at the NET clinic at Royal Free hospital, Hampstead, London.”*

Some examples of negative comments are:

*“Operation has had long term effects due to the complications during surgery. I have no recourse for this, have tried legal advice, but to no avail. I can no longer work due to illness; this should be looked into for patients.”*

*“This patient has terminal cancer. Treatment has now finished.”*

#### **4.4.11 After Care**

There were 15 comments around the provision and quality of after care, 6 were positive and 9 were negative. The negative comments focused on lack of services and feeling isolated and alone. Also negative comments covered patients being very pleased with their care during surgery, but then it going vastly downhill for the aftercare - particularly if they had to go to a different hospital (often away from the specialist NET centre).

Some examples of positive comments are:

*“My cancer was discovered through bowel cancer screening. I am very pleased with the aftercare I am getting. Everything get explain to me so I can understand and I can ask questions.”*

*“Excellent since diagnosis, but it took more than [number removed] years to get there. Labelled as IBS.”*

Some examples of negative comments are:

*“Some questions do not really relate to my situation. I went straight into local hospital; they did not know what I had until after biopsy. NHS service was great. Aftercare not so good.”*

*“Nobody seems to listen to me and I feel like I’m being fobbed of most of the time. My consultation sessions last for about 15 minutes and then I never get direct answers to any of my worries. Nobody seems to give a damn.”*

#### **4.4.12 Net Patient Foundation**

4 comments were made specifically about the Net Patient Foundation. All the comments were positive and referred to the excellent information and support they received when making contact.

All of the comments relating to the Net Patient Foundation are below:

*“My care/treatment for NET tumour has been excellent by the cancer specialist nurse and I have been treated as an individual. When she was off sick and I had a second cancer diagnosed, the staff at the local hospital had little knowledge about NET cancers. The NET Patient Foundation was invaluable at this time and were very supportive.”*

*“After lobe removal, my consultant considered me cured and I was not referred to a specialist in this type of cancer, so I researched and found the NET patient forum. They advised me about the correct procedures and NICE guidelines, so I then requested my GP to refer me to the Royal Free at Hampstead, who have been excellent.”*

*“Specialist nurse told me to look NET up on internet - was fast growing. She avoided most questions, told me must have chemotherapy. Website said something different. Discovered NET Foundation. Saw chemotherapy cancer consultant. I insisted on seeing NET consultant (Foundation information), finally agreed chemotherapy as scared witless.”*

*“The nurse here is brilliant as is the surgeon. My consultant is also excellent. The endocrine specialist is more elusive and hard to contact. NET [Patient Foundation] have been very helpful in providing information and support.”*

## **5. Conclusion**

This survey has provided one of the largest data sets worldwide regarding NET patients' experiences of treatment and care, with just under 1000 respondents taking part. Much of the data is comparable to the National Cancer Patient Experience Survey (CPES) results - one of the most influential surveys which is undertaken yearly in England.

The results from this survey -and the comparisons we are able to make - give a worrying picture of NET patients' experiences especially compared to other cancer types. Even when the CPES data is broken down by tumour type, NET patients report less positive results than even the lowest scoring tumour group. This is especially so with regard to information and support; feeling involved in decisions about care and treatment; and on care from their GP. The survey also highlighted the fact that NET patients have a much longer journey to diagnosis which can result in their condition worsening before they get treatment.