



The purpose of the NCUK Barriers Survey was to consolidate and add to previous national and global Neuroendocrine Cancer (NC)* patient experience surveys and reports, to gain further insights into the patient pathway for those diagnosed with NC. From initial symptom, through seeking advice to diagnostics and treatments - does current experience of Neuroendocrine Cancer care confirm the influential factors identified in previous cancer care reports?

Are there particular differences - and if so what are these?

From our community - what is the current situation, what is working and what recommendations would they suggest to address the barriers identified?

*Neuroendocrine tumours (NETs), neuroendocrine carcinomas (NECs), neuroendocrine neoplasms (NENs) and carcinoid tumours are collectively referred to as 'neuroendocrine cancer'.

In and across the UK, various initiatives have been implemented to try to overcome barriers to early and appropriate diagnosis of cancer, including public awareness campaigns, cancer wait time directives, improving outcomes guidance and commissioned care - however, these predominantly focus on more common cancers - or specific population groups for example age group targets.

And although early diagnosis programmes, thought to be comparatively easy and inexpensive to implement, can be effective; they primarily target symptomatic patients, specifically those with well defined 'alert symptoms' and therefore exclude those who do not fit within such strict criteria.

NCUK Barrier's Survey

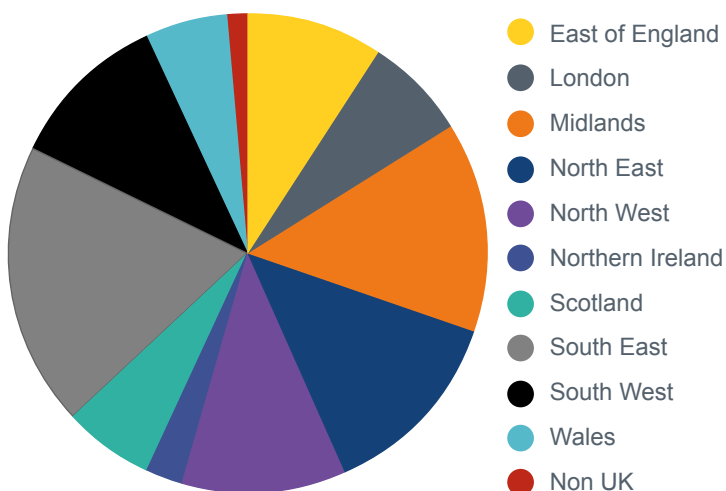
Utilising Smart Survey, NCUK social media platforms, membership mailing list and website, we asked for members of our community to share their experiences of care to date.

Our survey comprised of 32 questions - with a mixture of closed, open and free text answer options - and a predicted completion time of 15-20 minutes.

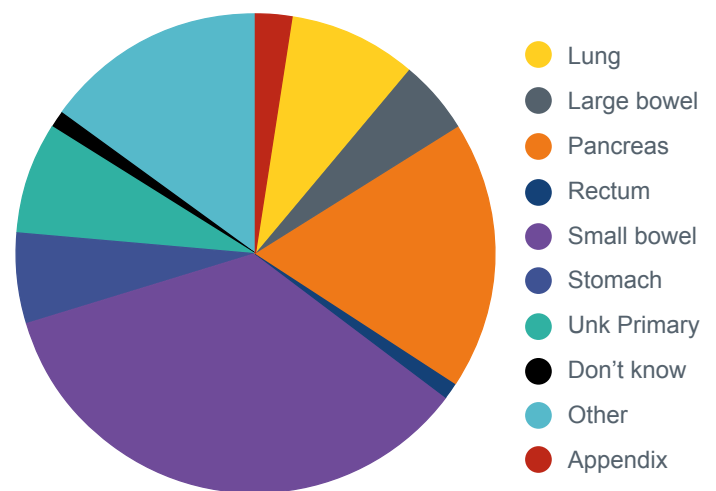
We received 880 responses: 197 partially answered and 683 fully completed. Responses were collated and a thematic analysis was undertaken of free text submissions.

Demographics:

A Geographical distribution



B Primary NC Site



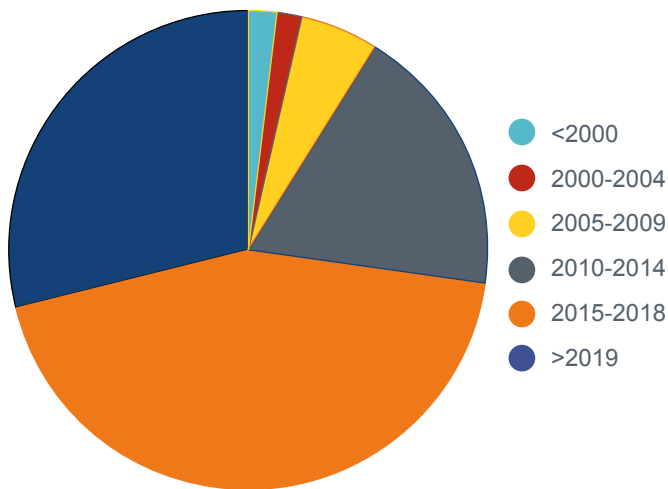


Primary site - included in 'other' were some of the primary sites listed, however there were differences in terms used - for example 'pulmonary' or 'thoracic' for lung.

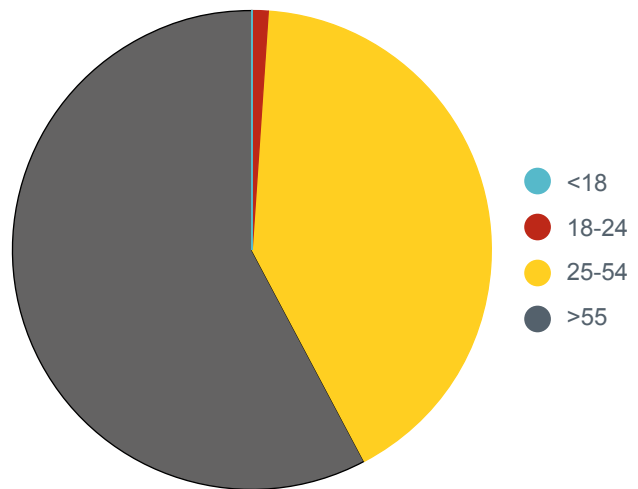
Other sites mentioned included eye, cervix, ovary, breast, thyroid, thymus, kidney, bladder and adrenal gland.

Skull base and head/neck were also noted - 10/11 clarifying paraganglioma as diagnosis.

C When Diagnosed



D Age at Diagnosis



Age now:

3 in the under 24yr age group (9 at time of diagnosis (TOD))

197 in the 25-54 yr group (235 TOD)

475 are 55yr or older (384 TOD)

First symptom noticed and when health advice first sought

There are a number of influential factors that have been identified as playing a part in when and whether people seek health advice if feeling unwell or 'not quite right'.

Trivialising or normalising a symptom has been identified as a deterrent, alongside not wanting to 'bother' the doctor, use of self-care interventions, a fear of investigations and/or potential results.

Motivations include persistence or severity of symptom, "instinct" / body awareness and social influence e.g. partner prompting or making appointment.

In a survey (Basuroy et al 2017) there was a clear demonstration, amongst a select NC population, that reduced health seeking behaviour was not an issue, in fact 80% of respondents visited their GP on average 11 times (related to the symptoms from NC) and secondary care an average 3 times prior to diagnosis.

This would appear to suggest that the deterrents mentioned above do not apply - and that delays in care may be more attributable to a lack of appropriate onward referral or appropriate investigations in the primary and secondary care setting, rather than healthcare avoidance.

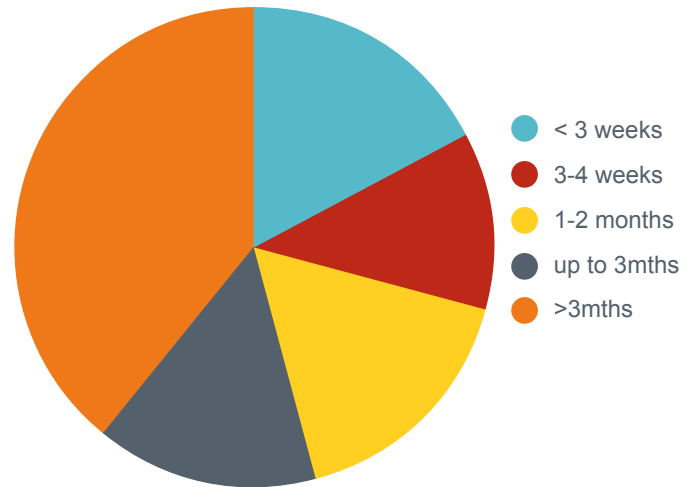


But is this an accurate conclusion?

Certainly delays occur after first seeking health advice for a number of reasons, but what occurs between experiencing first symptom and first seeking advice.

Approximately one fifth of our respondents said that they had sought advice within 3 weeks of experiencing 1st symptom (the majority describing pain).

Two-thirds sought advice within 12 weeks - primarily due to persistence or worsening in symptoms.



It was slightly more difficult to assess response in the >3 month group - as in fact many had sought advice:

I had been to the doctor numerous times over a period of 5 years before I was referred to a hospital was passed around for 3-4 years.

Whilst others confirmed the ‘normalisation’ effect:

It seems strange to say, but I didn’t really notice the weight loss, but, really, just not feeling right, what i called at the time, (in a joking way) feeling like i had lost my mojo!

I got used to feeling the way I did and thought it was normal.

Assumed the weight loss was down to the ageing process.

I didn’t seek advice been diagnosed as per diabetic and thought that was cause.

I tried to treat my symptoms with tablets from my pharmacy.

Motivators for seeking advice include persistence or severity of symptom, “instinct” / body awareness and social influence e.g. partner prompting or making appointment.

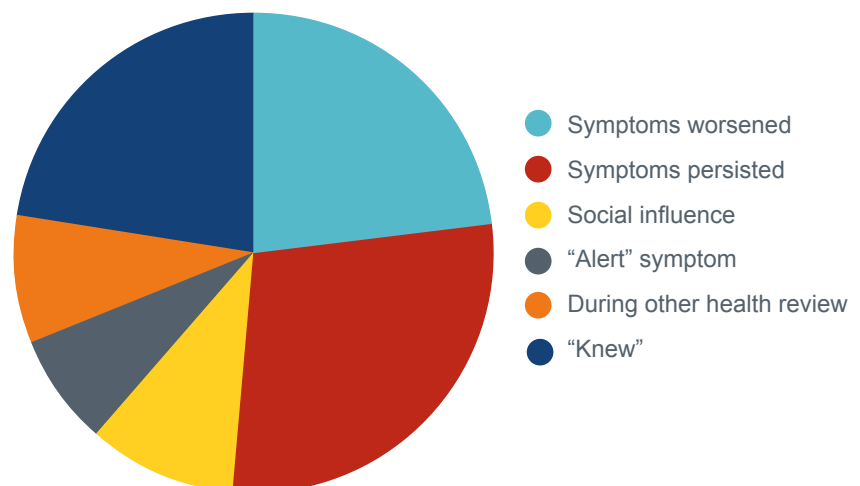
My wife noticed that the coughing was more frequent and persistent.

I just persisted. Pain was in the same place all the time.

did not seek further medical advice until my symptoms became much worse.

It was only unexplained weight loss that got me to thinking that this was more than IBS.

I had a gut feeling that something more was going on.





What symptom(s) did you first notice?

21% of respondents said that they did not have any symptoms they would attribute to their NC - with diagnosis being an 'incidental' finding - during routine health screen, tests / follow up for other health condition, a post-operative finding or due to other or due to other reasons e.g.diabetes, hypertension.



- Anxiety
- Bloating
- Cough
- Constipation
- Diarrhoea
- Flushing
- Heartburn/reflux
- Pain
- Palpitations
- Fatigue
- Unexplained kg loss
- Wheezing
- IBS- symptoms
- Other

Other symptoms including:

- Nausea +/- vomiting
- Appetite loss
- Feeling a lump
- Urinary Tract Infection
- Recurrent Infections
- Anaemia
- Jaundice
- Poor swallowing
- Bleeding - PV, PR, coughing (haemoptysis)
- Temperature intolerance / night sweats
- Skin changes - hives, rash, irritation
- Allergy-like reactions
- Ankle swelling

Referral for investigations / to hospital

More than half of our respondents were referred for further investigations or secondary care review by their GP

- 20% presented through A&E
- 20% were referred on by hospital doctors they were seeing for another condition

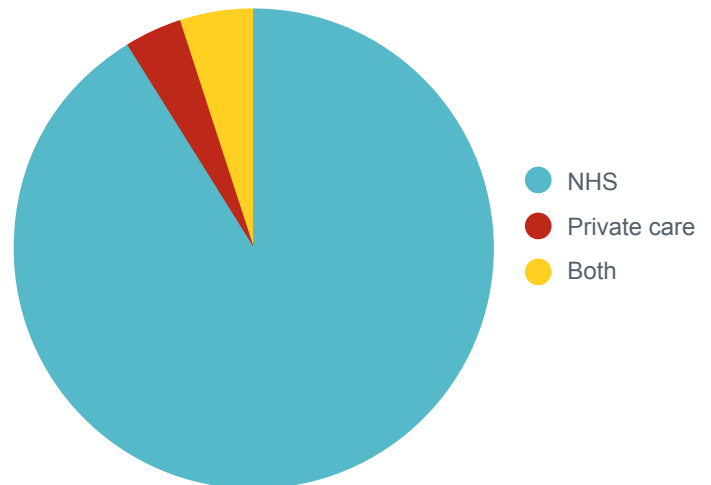
A small number of people accessed further investigations through private care.

Of those referred on by primary care: 33% were referred to Gastroenterology - less than 3% were referred directly to a Neuroendocrine Cancer Specialist team.

If referred by a hospital doctor - specialist team referral rose to 8%.

52% of respondents receive a diagnosis of Neuroendocrine Cancer following first referral to secondary (or tertiary) care.

Of those who did not receive a diagnosis at this time - a third returned to their GP - with 29% visiting a further 1-2 times before being diagnosed, 17% visiting 3-5 times, 7.5% visiting 6-8 times, 5% visiting 8-10 times and 16% visiting more than 10 times before obtaining an accurate diagnosis.



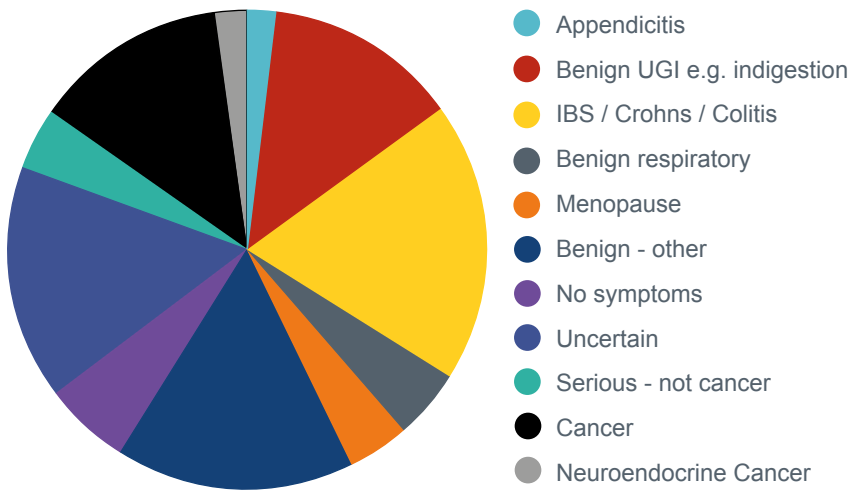


For those who continued through secondary care - 40% had 1-2 visits before receiving a diagnosis of NC, 32% visited 3-5 times, however >28% required more than 6 further visits (12% more than 10).

Initial diagnostic tests included blood tests (75%) and CT scan (67%), with functional imaging infrequently used (<20%). Almost half (44%) report having a biopsy.

We asked respondents what explanations were given for their symptoms if NC was not diagnosed - diagnoses given included asthma, IBS, menopause, anxiety, cyst or benign tumour, other cancer - including pancreatic, melanoma, lymphoma, which would support earlier findings - Basuroy et al - where <4% of primary care suspected cancer (<17% of secondary care), and <2% of those suspected Neuroendocrine Cancer (24% in secondary care).

We also asked what respondents suspected might be the reason for their symptoms:



Neuroendocrine Cancer was suspected by those who had either a family/ personal history (e.g. family member who had had NC - or an individual with a NC related genetic condition) or who had read an article or newspaper story that seemed to resonate with their symptoms/experience.

Following diagnosis

Until now not mentioned, a further potential barrier to accurate diagnosis, is that of terminology - which may also influence likelihood that NC is included as a possible diagnosis.

So before looking at the treatments and care started on receiving a diagnosis, we were interested to find out how diagnosis was explained - what term was used.

According to respondents - 61% were told that they had a Neuroendocrine Tumour, Carcinoma or Cancer. However, even within this group, the word cancer was not always used:

Referred to as tumour in 2015-16. Did not hear the word Cancer used until 2019.

Others describe not hearing the word Neuroendocrine or Cancer until just before or after surgery. Other terms included Carcinoid or Tumour - without further explanation - or were told it was not "really cancer".

Was told it was a neuroendocrine tumour but had to ask if this was cancer as cancer not mentioned.

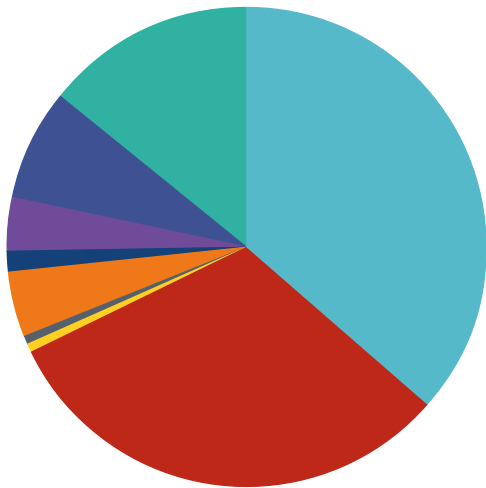
After an emergency admission 2 years after initial IBS diagnosis. Surgeons requested a CT and advised I required surgery for a little bit of something that was not a cancer really .

1 in 5 saying that they found out from either a leaflet, clinical letter, or at a much later date.

About six months after diagnosis. | Through the internet and social media groups. | I think I read it on a leaflet from the hospital. | When my information pack arrived in post. | I was told it was a carcinoid tumour. Later I heard the term of neuroendocrine on Facebook.



What was first treatment ?



- Surgery
- SSA
- Interventional radiology
- Interventional endoscopy
- Chemotherapy
- TMT
- NM
- Surveillance
- Other

SSA = somatostatin analogue (Lanreotide - Somatuline Autogel, Octreotide - Sandostatin LAR or Olutaton) Interventional radiology included embolisation and ablation.

TMT = Targeted Molecular Therapies (Everolimus, Sunitinib).

NM = Nuclear Medicine (Selective Internal Radiation Therapy {SIRT}, PRRT {Peptide Receptor Radionuclide Therapy - Lutetium 177, Yttrium 90 or MIBG}).

Other treatments included clinical trial, palliative care or other medications, for example, high dose PPI in Gastrinoma or alpha-blockers for pheochromocytoma.

Before asking for suggestions regarding where improvements might be made - we wanted to know whether respondents had a specialist Neuroendocrine Cancer Team involved in their care.

77% replied that they were under the current care of a specialist NC team.

Originally under general oncologist then a gastro endro oncologist and finally a neuroendocrine specialist team after 6 years at 3 different hospitals.

Yes, but I had to pursue it through my GP to get referred to one.

We asked several times but went for a second opinion referral to special NET team

I am BUT only after constant requests to GP and Oncologist which were originally 'humoured'.

Yes but only because I fought to be seen by the specialist team

3% said that they had been seen but were now under local care only.
<1% had been referred but were waiting to be seen.

Of the remaining 19% - respondents said that they were not aware that there was a specialist team, that they had never been referred, that they had been mentioned but logistically difficult to access (geographically) or were under a site specific team, for example respiratory care.

Never been discussed or given the option.

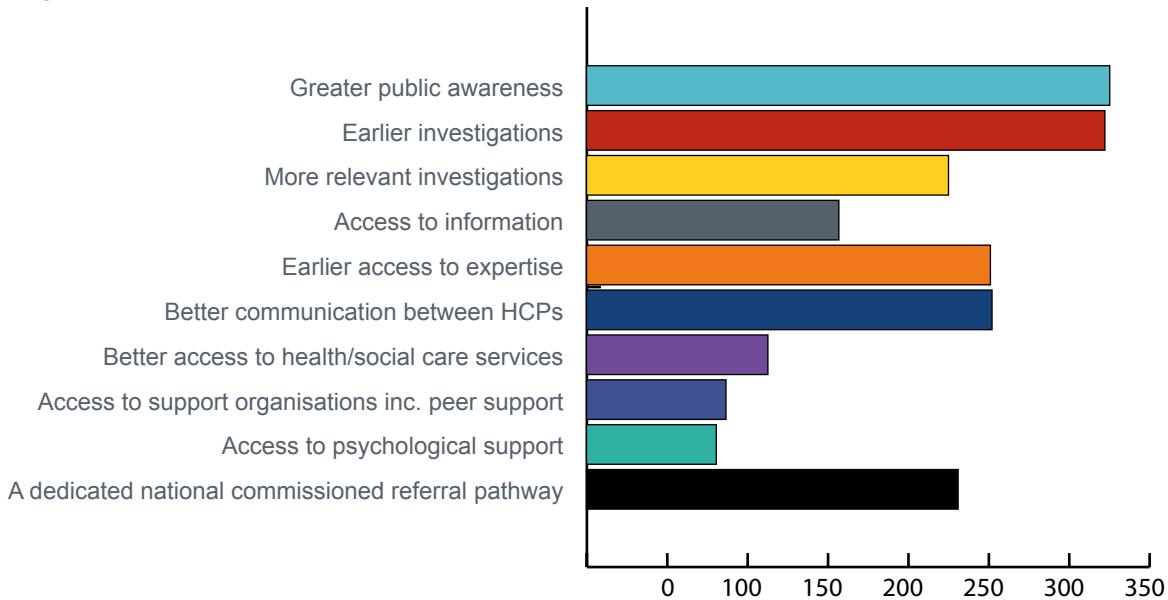
My thoracic surgeons. . .NET consultant was included in MDT at the start. . . but I haven't seen one.

So whilst many are under specialist care - referral and involvement is not clear cut - and often patient-driven, which may be due to absence of nationally commissioned dedicated pathway and service provision.



NCUK Community Recommendations

We asked our community - If anything, what might have made your journey to a Neuroendocrine Cancer diagnosis easier?



Probably a bit of all these are relevant, as i have said, it is so hard for doctors, as symptoms are easy to miss, but I did feel like my doctor was not as aware as maybe he could have been about what my problem could be, but I know this may be unfair as its so difficult for things to be picked up, when I first went to the doctor, it could have been any number of things. I did feel though, that it was only through my persistence that I got anywhere.

Awareness and Pathway of Care:

Awareness

My GPs unfortunately did not look for other alternatives apart from IBS over a period of a couple of years of worsening symptoms.

*Had never heard of NET so **awareness is crucial**. A surgery nurse friend had never heard of it either so **awareness among health professionals needed** more.*

The biggest problem was my GP as would only run blood tests and I had to persist to get referred as they didn't achieve anything during the 4 years I was being seen. As soon as I was referred I was given a urine test and they found it straight away.

The initial biopsy and surgery at _____ - was world class but they continued to monitor my lungs rather than taking a more general approach, I have an atypical carcinoid and as a result blood tests, etc. are often 'normal'.

***You would have expected that** as part of the MDT process **the net team would've been involved** - in my treatment **but they were not**.*

***A decision was made for a pet scan but the wrong one was given** and it did not show the net in the bones.*



Faster access to definitive investigations.

A better cancer referral pathway in general. A GP could only refer me to investigate one possible cancer at a time. Did ovarian, then lower GI (where they saw the growth on pancreas) but then referred me on to upper GI. My weight loss was dramatic - cancer was highly suspected I'm sure, but it took from GP in October 2018 to oncology in Oct 2019 to get the diagnosis. If I have had a scan in Oct 2018 it would have been found sooner and more treatment options would have been available.

Communication, Information and Support.

*My initial diagnosis was very poorly handled in terms of how it was **communicated** to me. Both the GP and the gastroenterologist showed **little experience or understanding of the condition** and appeared to have no training in delivering bad news to a patient. If not for the **support** of NCUK and Maggie's Centre in the first 12 months post diagnosis would have been a very lonely and difficult place for me and my partner.*

***Information given to me earlier.** Seemed to be hiding the cancer.*

*I have struggled with **finding information** initially and health professionals treating new patients as it's nothing to worry about . I have found the journey painful and only when I asked for some support after feeling deflated and helpless because I felt alone . Was I then given the **support group near me which has been a lifeline.***

*I had to wait a long time after my surgery for the results because it was discussed by a MDT. **I was not told what an MDT was or why they had to discuss my case.** I was then told that the lump they removed contained neuroendocrine cells something else that I've now forgotten. That was it. So I said it's benign isn't it and the surgeon said well if you take a scale of 1 to 10 for cancer some cells in my lump would be about a 5 and some would be a 0 so on average it would be a 2 to 3. That was it. . . **nobody stood up and said I had cancer or any support to go with it. I was left to Google it** and went into complete malt down. Thank goodness I found the phone number for the NCUK - they were wonderful and spoke to me for a long time, educating me on what I had, what I should do and was amazing. Before calling NCUK, I had phoned the Macmillan help line and they had never heard of NET cancer. She told me to ring back when I had more information about it!!!*

Conclusion

It is perhaps unsurprisingly that recommendations to improve NC diagnosis and management were as reported above.

This survey re-confirms earlier work by NCUK and allied organisations and healthcare professionals (Basuroy et al and INCA - Bouvier et al, Leyden et al and Singh et al) - and this strengthens the evidence base for making a change to the current situation - to add to and further develop existing initiatives such as dedicated commissioned pathways and improving outcomes guidance - to include NC.

There is a clear need for the development of well-defined diagnostic and care pathways and investment in resource capability, awareness and education to ensure efficacy in access to both appropriate diagnostics and treatments : and patients as partners in care is an absolute requirement for improvements in both experience and outcomes. This includes building and maintaining stronger relationships across all stakeholders - patients, their families, patient organisations, health care professionals, providers and policy makers - all invested in care.

Only then can we start to see the pulling down of barriers and an improvement in experience and outcomes.



We would like to offer our sincerest thanks to our community for their response and involvement in this survey - and for sharing their experiences. We will be sharing results on our website - and also utilising this information in our BRIDGING the GAP campaign to help bring about the change(s) needed.

References

- Basuroy R et al (2018) Delays and routes to diagnosis of neuroendocrine tumours, BMC Cancer volume 18, Article number: 1122
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- Singh et al. (2017) Patient-Reported Burden of a Neuroendocrine Tumor (NET) Diagnosis: Results From the First Global Survey of Patients With NETs. J Glob Oncol.;3(1):43-53.
- Whitaker et al (2015) Help seeking for cancer 'alarm' symptoms: a qualitative interview study of primary care patients in the UK British Journal of General Practice; 65 (631)

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