

JANUARY 2022

Not Just NE Cancer Series

Just Diagnosed Survey Results.



ABOUT NEUROENDOCRINE CANCER UK

VISION

Our vision is of a world in which people know how to recognise, diagnose, treat, care for, and ultimately, cure patients with Neuroendocrine Cancer

MISSION

Our purpose is to support and inform patients and families from diagnosis, enabling access to the best care and treatment, whilst stimulating Neuroendocrine Cancer research, increasing national awareness and influencing improvements in outcomes.

About the 'Not Just NE Cancer Series'

Our focus, message and slogan for 2022 is 'NeuroEndocrine Cancer is not just NE Cancer' and this year NCUK will educate, inform and support its online community by taking viewers on a virtual journey right from symptoms prior to diagnosis through to treatments, follow up, and looking after your emotional wellbeing etc.

Included in the series, our online community will have access to the following:

- Informative, educational and supportive online content
- Real-life patient experience videos
- Monthly podcasts
- Educational videos from the experts
- The opportunity to 'Have your Say' in our monthly survey
- A chance to feature in our Faces & Voices of NCUK campaign.

Summary of Results

For this month's survey, we asked our online community about their Neuroendocrine Cancer diagnosis. We obtained responses from 241 participants from across the whole of the United Kingdom.

Thank you to everyone who completed the survey you have not only provided us with a better understanding of the community's needs, you are also helping drive our future projects and plans. We want to ensure that the work we do, will be most beneficial to all affected by Neuroendocrine Cancer.

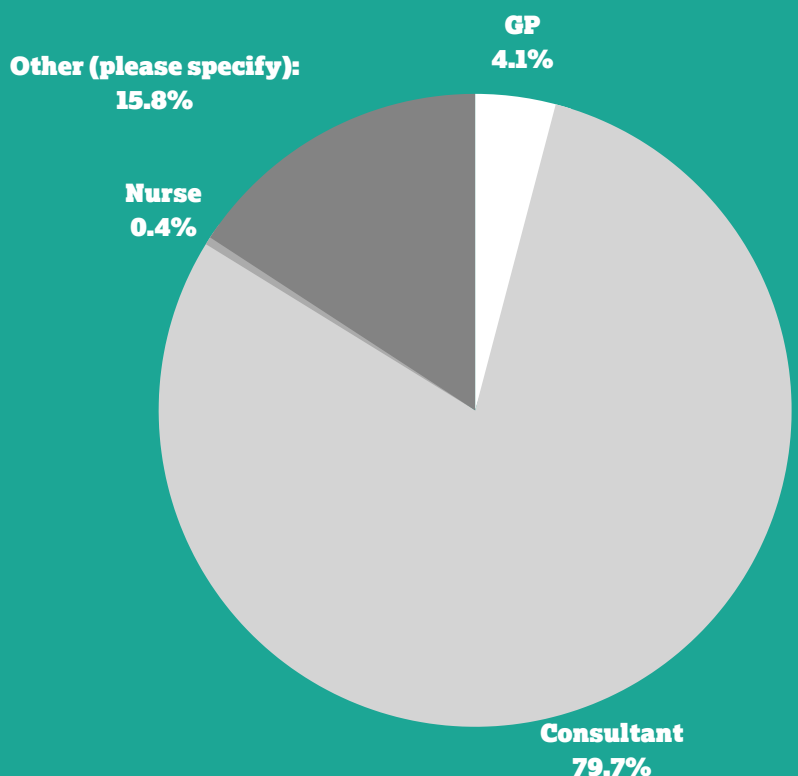


Q1. WHICH HEALTHCARE PROFESSIONAL DIAGNOSED YOUR NEUROENDOCRINE CANCER?

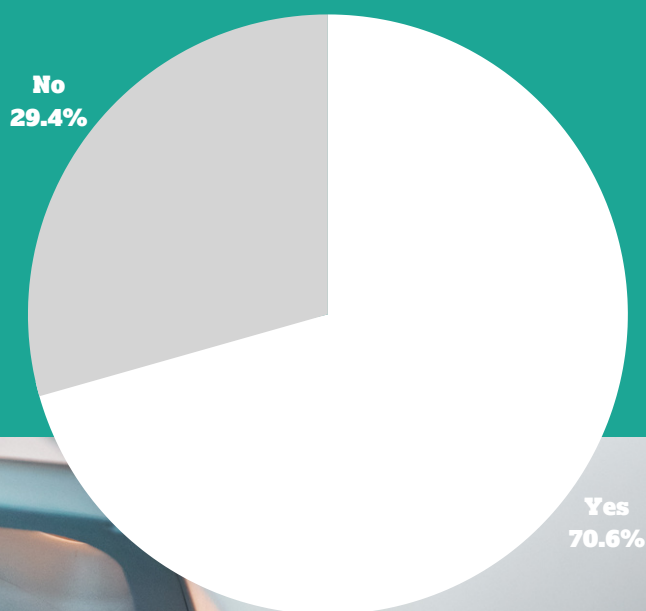
- GP: 4.1%
- Consultant: 79.7%
- Nurse: 0.4%
- Other: 15.8%

Others included:

- Gastroenterologist
- Gynaecologist
- Oncologist Surgeon
- Physiotherapist
- Radiographer
- Urologist.



Q2. IF YOU WERE NOT DIAGNOSED BY A SPECIALIST NEUROENDOCRINE TEAM, WERE YOU REFERRED TO A SPECIALIST NEUROENDOCRINE TEAM POST DIAGNOSIS?

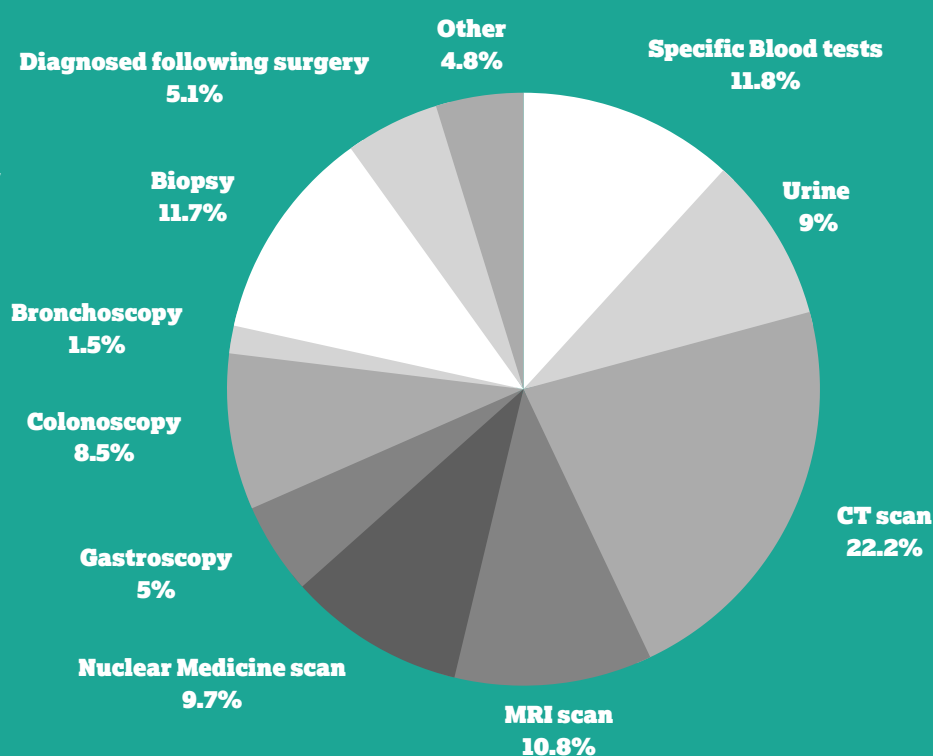


Q3. WHAT INVESTIGATIONS OR PROCEDURES DID YOU HAVE PRIOR TO DIAGNOSIS THAT LED TO YOUR DIAGNOSIS?

- Specific Blood tests: Chromogranin A/B, Gut Hormones, Metanephrines, Catecholamines
- Urine: 24hour collection or other for 5HiAA or metanephrines/catecholamines
- CT scan
- MRI scan
- Nuclear Medicine scan: Octreoscan / Tektroyd / Gallium 68 Dotatate / MiBG scan / FDG-PET
- Gastroscopy
- Colonoscopy
- Bronchoscopy
- Biopsy
- Diagnosed following surgery
- Other.

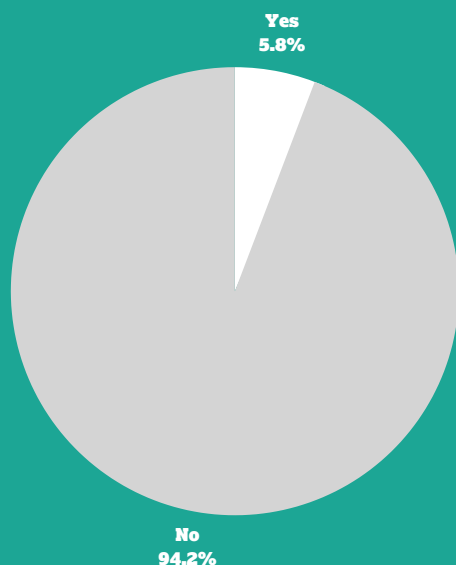
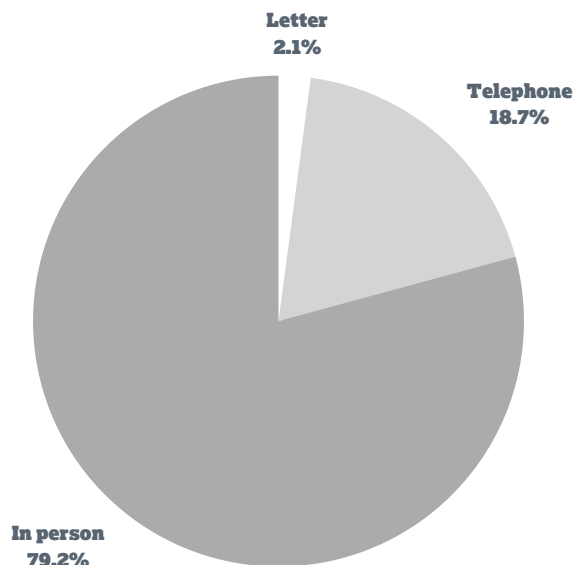
Others included:

- Capsule endoscopy
- Ultrasound
- Colonography
- Hysteroscopy
- Ileostomy
- Mammogram
- Post hysterectomy ultra sound picked up lump on liver.





Q5. HOW WERE YOU TOLD ABOUT YOUR DIAGNOSIS?



Q6. HAD YOU EVER HEARD OF NEUROENDOCRINE CANCER BEFORE YOUR DIAGNOSIS?

Q7. IF NEUROENDOCRINE CANCER WAS NOT TERM USED FOR YOUR DIAGNOSIS - WHAT WORDS WERE USED TO DESCRIBE YOUR DIAGNOSIS?

Something on the end of your appendix!

malignant insulinoma

Menopause, IBS

Cancer

A good cancer to have

NET

Liver Metastasis

**Small cell,
aggressive
Carcinoid**

**Colorectal or Gastro
Intestinal Stroma Tumour**

DIPNECH

Pancreatic Cancer

Neuroendocrine tumour

NEC

A small spot on your lung



Q8. WHAT HELPED YOU MOST WHEN FIRST DIAGNOSED?

- Feeling listened to by my endocrinologist
- Seeing a professor who explained things in layman's terms
- Being kept fully informed about the diagnosis and further investigations. Having named contacts with specialist nurses was invaluable as I could ring them with any questions
- My inner strength & new positive attitude came to the fore when those words 'Cancer' was used. This outlook & positive mindset helped me through
- Talking to a good friend, who has helped me a lot
- Knowing that I was under the care of specialist people who understood my disease
- Being told the truth
- Learning about NEC
- Information from recognised cancer organisations - Neuroendocrine Cancer UK, Macmillan, Cancer Research UK, Maggie's
- Facebook groups and local NET support group
- Walking. Reading. Singing.
- Access to Cancer Nurse Specialist
- Being told it was a manageable cancer
- When I was told of the slow growth rate and the possibilities of life
- Reading others stories
- Support of friends, seeking counselling
- The relief of finally finding out what had been wrong with me for years and being able to have something done about it. When I got home music was my saviour while I processed my cancer status
- Very little. Diagnosis was a bombshell. More or less left to me - I did not know who to contact and, to be truthful, I did not want to know more
- Nothing. It was hell. Until I found NCUK, I felt like an Alien. Getting information and understanding what was happening was wonderful

Q9. WHAT ADVICE WOULD YOU GIVE TO SOMEONE RECENTLY DIAGNOSED?

- It's a marathon not a sprint - Document everything
- Write a list of questions before appointments
- Take someone to appointments who can take notes for you
- Speak to the experts about everything you're unsure of, don't let your mind fill in the gaps in your knowledge
- Reach out to Neuroendocrine UK - it's a remarkable resource, both for information and connecting with others
- Do not think that the life is over
- Take each day as it comes - you will have good days, however you will also have good ones too. Listen to your body. If you need to sleep during the day then do it.
- Keep asking questions and don't be afraid to mention new symptoms even if they turn out to be nothing
- Take the time to step away from your work, phone and computer to take the diagnosis in. Nothing will change if you take a few hours to absorb the news! Gather your thoughts and Breathe!
- When ready tell friends/ work/workmates. I didn't tell work mates until 6months after diagnosis and wish I'd told them earlier
- Ask to be referred to a specialist NETs team
- If you live near a Maggie's Centre go there. Or make contact online
- Seek out and try some counselling or other Psychological Therapy even if you are not sure you need that.
- Have a 24 hour helpline number to hand
- Don't despair - you can still enjoy life, even if it is different and talk things through with a neuroendocrine specialist nurse
- Use internet sites with caution. I have frightened myself big time! It is difficult especially at the moment to get results but I have found NCUK brilliant and supportive and I would advise a newly diagnosed patient to make contact with their particular issues as everyone is different in their disease.