

FEBRUARY 2022

Not Just NE Cancer Series

Tests & Getting Your 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.

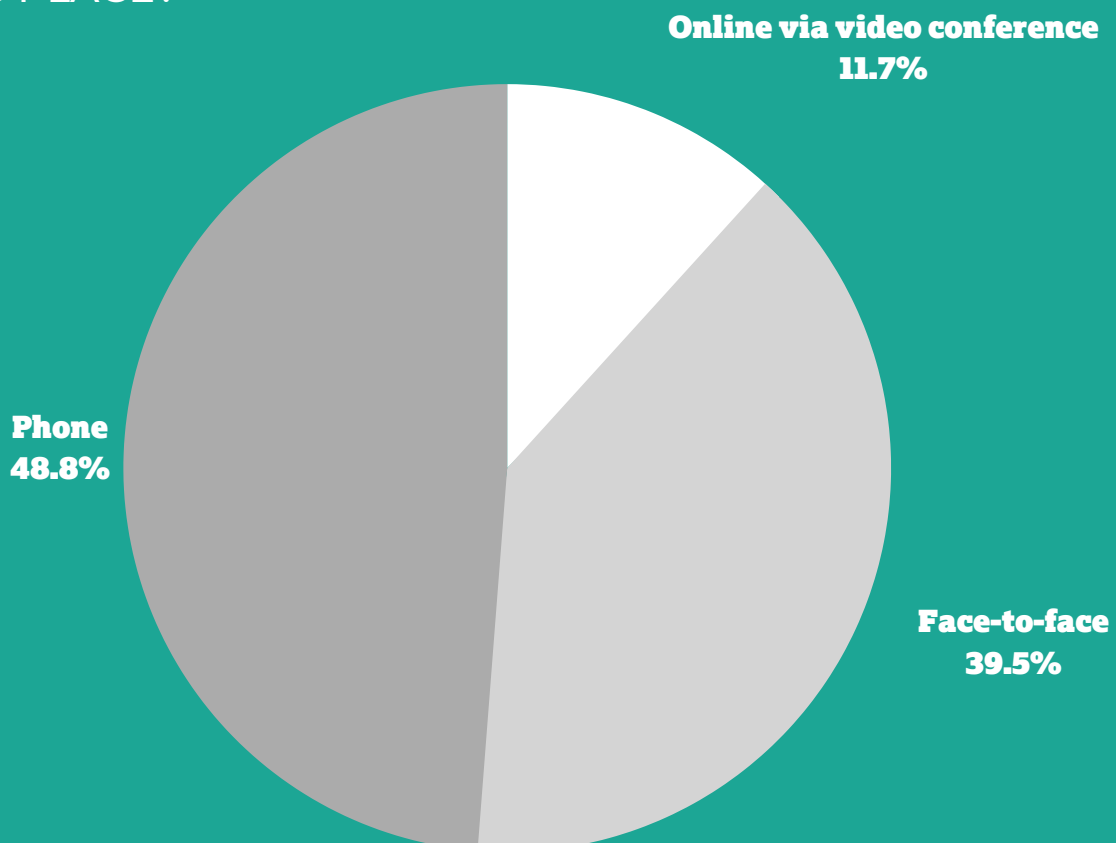
Summary of Results

For this month's survey, we asked our online community about their Neuroendocrine Cancer tests and results. We obtained responses from 149 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.



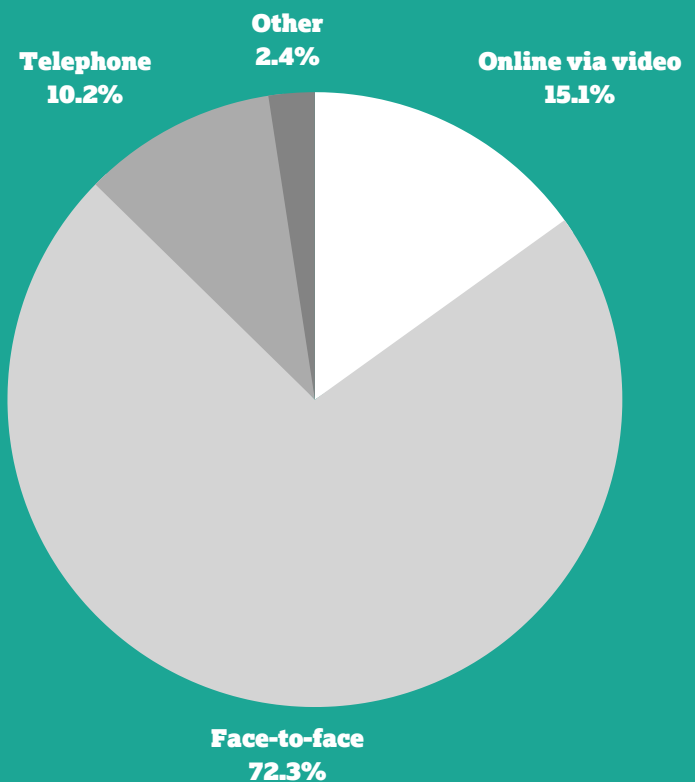
Q1. HOW ARE YOUR CLINIC APPOINTMENTS CURRENTLY TAKING PLACE?





Q2. IF YOU HAD A CHOICE, WHAT WOULD YOU PREFERENCE BE?

- I am given a choice which is good
- Mine are two yearly post scan, so not concerned how they happen
- Alternate video and in person



Q3. DO YOU HAVE ANY ADVICE ABOUT GETTING THE BEST OUT OF YOUR CLINIC APPOINTMENT?

- Think about what you want to get out of the session and formulate your questions
- Difficult not always know what is discussed, maybe a follow up phone call from CNS. Write questions down and try and get the clinician to summarise
- Do your own research so that you can understand what you are being told and be prepared for your clinician to have no idea regarding NETs
- Keep good records of symptoms even the ones you think are not relevant
- Make sure a family member or a friend to accompany you for support
- Prepare your questions beforehand and go over them again and again as it's easy to forget something once you're in the clinic. Take a small notebook with you to make your own notes or use the record function on your phone.
- Speaking face to face, and getting your scan and blood results quicker to save on stress levels
- Always be polite, be patient. When your consultant or nurse ask you if you have any questions - "No, but are there any questions you think I should be asking"
- Ask for a printed copy of bloods and scans, discuss at appointment
- Expect delays. That way, no stress involved. And if things run on time, it's a bonus.



Q4. WHAT ARE THE BEST WAYS YOU'VE FOUND TO COPE WITH HAVING INVESTIGATIONS E.G. SCANS?

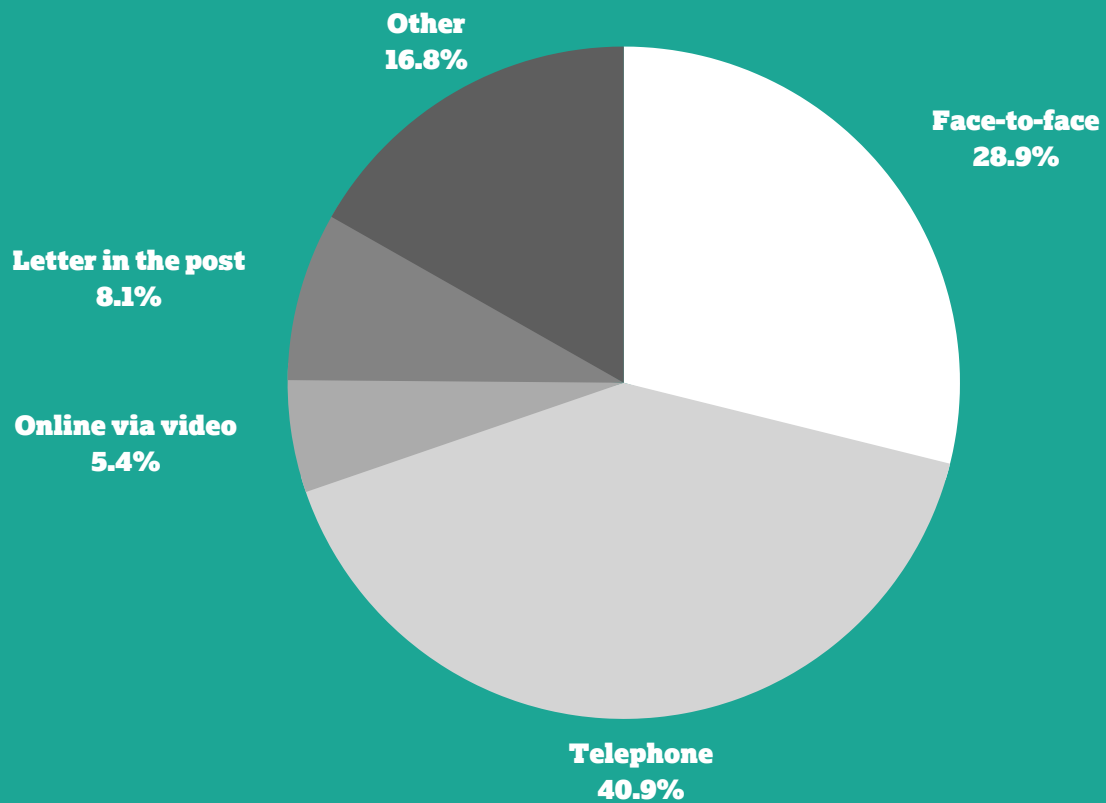
- Knowing that these help, in either monitoring or investigating. They don't hurt, and the technology is amazing
- Listening to music
- Experience! I've had so many I'm quite relaxed about it. Still keep my eyes closed in a MRI scanner, and not keen on cannulas. Be well hydrated for anything blood related
- Talk to my support nurse and share with my husband
- Distractions like work, running etc in between
- Just accept that they are necessary. The first MRI scan can be scary, but you gradually get used to them. Check that you are wearing suitable clothing, and that you are not wearing jewellery, piercings, etc. This reduces stress when you are getting ready for the scan
- Meditation
- Prepare well the day before so that you're not rushing around on the day itself. Leave early in case of delays on the journey, i.e. roadworks. Take something light to read whilst you're waiting. Promise yourself a small treat afterwards as a reward for getting through the scan
- Take time to relax, I always put a rest day on my calendar for the following day as you don't sleep well night before appointments or scans. Treat yourself to a relaxing bath
- Turn up prepared and informed about the investigation and/or bring questions with you
- Take each one as it comes, accept that it's a process to be gone through and discuss with whoever is your support both before and after. Try to remain calm, not always easy
- Just try and not stress yourself and keep positive
- Try to keep calm, concentrate on steady breathing and think about something nice
- Ask for assistance if you need it e.g. getting off the bed. Ask if there are any after-effects. Inform staff of any previous difficulties
- As a Muslim I've found being guided by my faith the most important thing
- Yoga, trying to stay calm. Stop myself going to worse case scenario
- My husband takes me to scans/appointments and is always waiting when I have finished. It's nice to have someone with you
- Mindfulness. Learn how to do guided meditations - they really help whilst having scans. I was sceptic but it really works
- Tell the Radiographer if you don't cope very well with cannulas etc, if they are aware of your concerns it will help get through having them done.



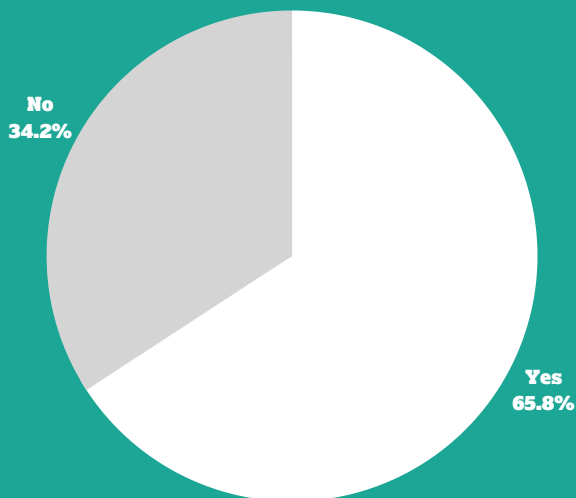
Q5. WHAT ARE THE BEST WAYS YOU'VE FOUND TO COPE WITH WAITING FOR RESULTS?

- To keep busy and doing activities I enjoy. I find staying at home and being alone causes me to worry and feel depressed
- I e-mail my specialist nurse when I think the results should be out, she will usually chase them and give me a brief resume
- I pray and talk to my friends. I try to be calm but it is always the wait that makes me on edge
- Running to make me tired enough to sleep better
- I expect them to take longer than they do
- Trying not to focus on them. Using a mindfulness app if possible, or playing some calming music. Using hobbies as a distraction therapy. Remind yourself you've come this far and tell yourself how well you're doing. Talking through your fears with trusted family and friends
- Keep your scan result date to a few close people, so if bad news you don't have to share until you are ready and processed it yourself
- Write questions ready for different scenarios
- I use the 'patient knows best' app, which gives me a date results will be shared, so I don't think about them until the date
- Live in the present. Deal with scan results on the day you get them. No point in projecting into the future. Could be causing yourself unnecessary anxiety
- Find distractions - hobbies, treats, try to maintain normal daily routines. Hypnosis scripts help me sleep. I keep a 'gratitude' journal where I write things I am thankful for
- I put it out of my mind as much as possible for the first two weeks if I know the results are going to take a while. Then I do a few "what if" scenarios to practice my real thinking. I always book my counselling appointment around the time.
- Read, I have a kindle device, I would rather read for the 5 awake hours in the night than fret and toss and turn
- Keep busy. I get very anxious before getting results but I have explained why to friends and family so they are aware why I am short tempered
- This isn't easy, all kinds of negative things may possibly be on your mind. Talk it through with family, contact a specialist nurse or neuroendocrine help line
- A few days before receiving results, have a plan of things to do to to keep yourself occupied.

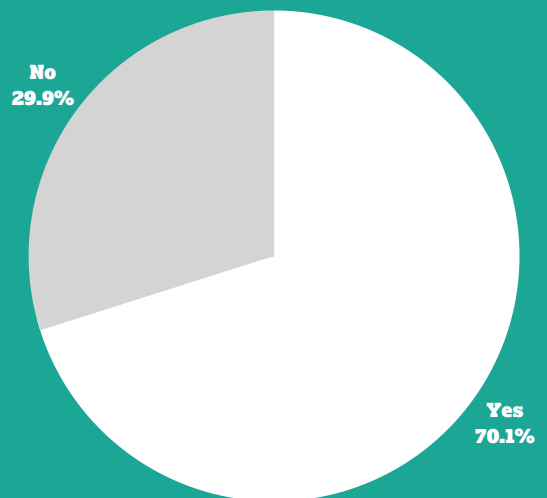
Q6. HOW DID YOU RECEIVE YOUR RESULTS?



Q7. AFTER INVESTIGATION(S), DID YOU FULLY UNDERSTAND THE RESULTS GIVEN TO YOU?

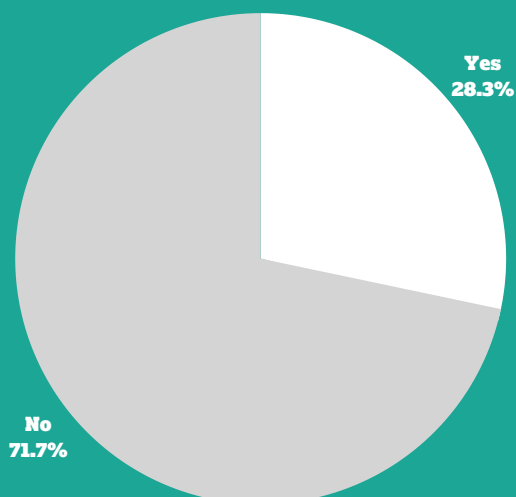


Q8. IF YOU ANSWERED NO TO THE PREVIOUS QUESTION, DID YOU FEEL CONFIDENT IN ASKING FOR FURTHER CLARIFICATION?





Q9. WERE YOU GIVEN
ANY INFORMATION TO
TAKE HOME WITH YOU?



Q10. DID YOU CONTACT US FOR
SUPPORT / INFORMATION /
ADVICE REGARDING YOUR TESTS
AND RESULTS?

