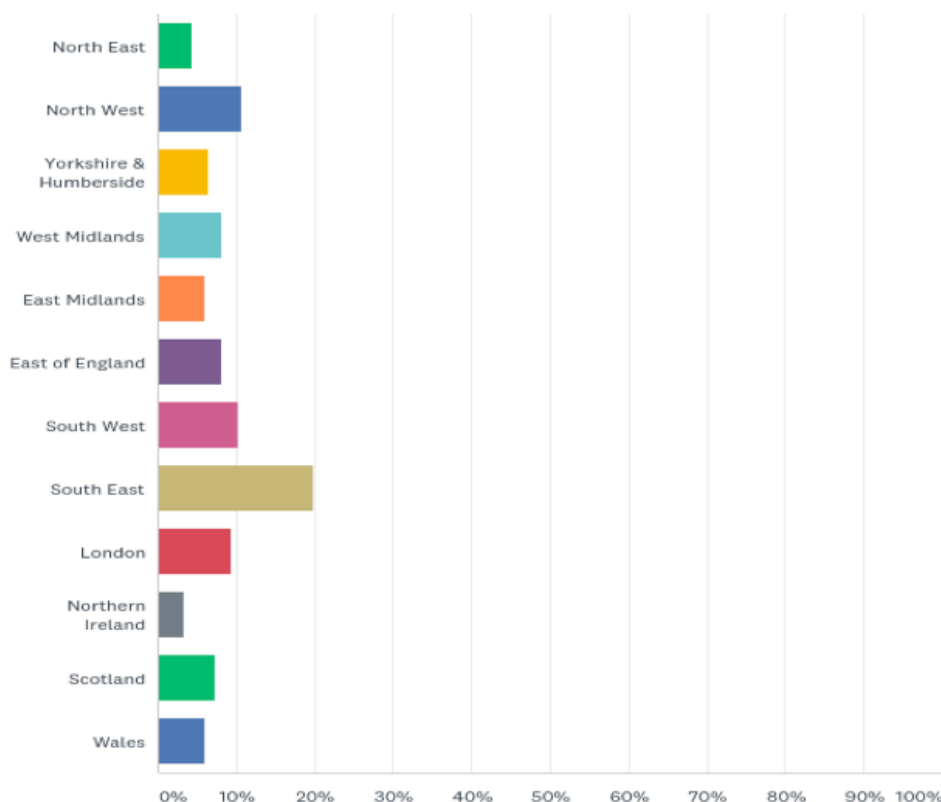


# COVID & My Care 2020

There is a real concern regarding the huge impact the Covid-19 Pandemic has had, and will have on healthcare for patients with cancer. To understand the impact this has had on the Neuroendocrine Cancer Community, a group often thought of as chronically rather than acutely affected, we undertook a survey. Utilising Survey Monkey, Neuroendocrine Cancer UK's social media platforms, patient database and NCUK website, we sought to obtain a snapshot of the effect this pandemic has had on patients' healthcare access and psychosocial needs.

We obtained responses from 361 participants from a fairly evenly geographical distribution across the whole of the United Kingdom. The majority of individuals completing the survey were linked to a Specialist Centre – the slightly higher proportion in the South East maybe reflecting the concentration of Centres within that region. Most of the respondents had a diagnosis of GEP or Lung based Neuroendocrine Cancer.



*Fig 1 -  
Respondent's  
Geographical  
Representation*

## Alterations in care

55% of respondents reported that the Covid-19 pandemic had affected their care, and this was both in the context of altered clinic appointments or commencement of therapy.

Around 45% of them reported their consultation had been deferred. Reassuringly only 4% of patients had a cancellation of an appointment with no further appointment agreed.

Of those who underwent a delay in their appointment, the delay was around 1 to 3 months however in some cases, the deferment was more than 3 months.

## Imaging

Scans have been postponed in 33.7% of cases - the majority of these were postponed by the hospital team, with only 9% receiving a new date.

Despite concerns raised in the media about delays being initiated by patients through fear of COVID only 3.4% of respondents reported this to be the case.

As seen in the delay in outpatient appointments, delays in scans appears to be around 1 to 3-months, although more than a third will have to wait more than 3 months.

*“WORRY AND ANXIETY FROM EVERY SMALL PAIN THAT IT IS THE CANCER RETURNED”.*

*“I suppose just hoping that I have not “missed out” on potential treatment/clinical trials or on having a wider expert team to consult at this stage of my disease”.*

## Treatment

Around 18% of patients have reported a change in their treatment due to the covid-19 pandemic. The primary change has been a delay in starting a new therapy or undergoing further cycles of therapy.

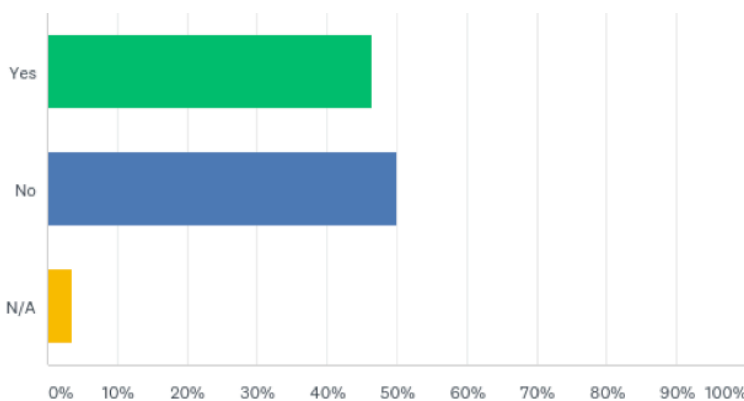
Reassuringly 65% of patients report no change in their treatment plan.

A significant proportion of individuals, around 30%, had blood tests delayed, 10% report delays in obtaining medications/ prescriptions, or alterations in the delivery or administration of their somatostatin analogue. A proportion of patients also expressed frustration at a lack of GP accessibility, blood tests and obtaining medication.

There have also been reports of interrupted B12 and bone health therapies (e.g. Bisphosphonates).

## Psychosocial impact

The psychosocial impact of the Covid-19 Pandemic is quite significant amongst survey respondents, with just under 50% reporting psychological symptoms. Increased anxiety and frustration induced by the pandemic and its knock on effect in accessing healthcare resources is notable.



*Fig 2 – Impact on Psychological Wellbeing*

ANSWER CHOICES	RESPONSES	
Yes	46.37%	166
No	50.00%	179
N/A	3.63%	13
TOTAL		358

From responses, only 2/3 of patients felt they had access to advice and support from their healthcare team during this time, and this was primarily from specialist nurses or from primary care.

1/3 of respondents did not receive any help from their specialist team, health care professional or other health care services, primarily because they did not make contact because they felt that they would be too busy dealing with COVID19.

An identifiable concern is that some patients reported that they did not have the contact information they may have required.

## **Conclusion**

This survey offers an insight into healthcare and social impacts of Covid-19 on the Neuroendocrine Cancer Community in the UK.

What is striking is the significant impact in terms of health anxiety and psychosocial well-being that has been felt by this cohort of patients – even for those, who are reasonably well and undergoing longer-term follow-up.

Whilst it is reassuring to note that many patients have been able to maintain access to healthcare and contact with their teams, for others there have been delays and cancellations of appointments, investigations and / or treatments – some with no further plans made, leaving them feeling adrift.

There are currently around 36,000 people living with Neuroendocrine Cancer in the United Kingdom. It is, therefore, vitally important that in recovering and restoring affected healthcare services, the anxiety and psychological distress that Covid-19 has added to individual's overall psychological burden should not be under-estimated.

We recommend that “recovery and restoration” plans need to include strategies and the infrastructure to address this increased need as ‘normal’ care resumes.