

COVID19 & My Care

There is a voiced genuine 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 more chronically 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, to date, 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 higher concentration of Centres within that region.

Most of the respondents had a diagnosis of GEP or Lung based Neuroendocrine Cancer.

Alterations in Care

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



Around 45% of them reported their consultation had been deferred. Reassuringly 96% of these patients had a further appointment agreed - leaving 4% with no confirmed plan of care or appointment.

Following operation and leaving hospital early due to Covid 19 I have had very little contact, no check ups no one to turn to or talk to, very little help advise of how to get better. Follow up has been delayed.

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

Delay of scan worries me in case something else has happened

Last scan showed mild progression, therefore keen to see results of next scan and whether progression has continued

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.

Treatment

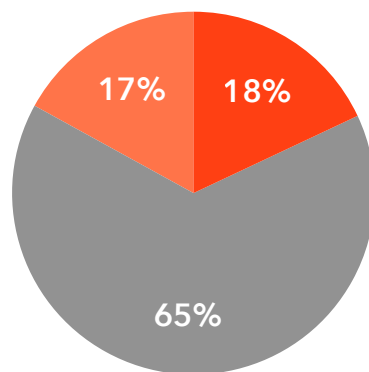
Around 18% of patients have reported a change in their treatment due to the covid-19 pandemic. The primary change has been a delay in starting a new therapy or undergoing further cycles of therapy.

...but symptoms worsening during this chemo break.

Resuming sunitinib instead of Lutetium 177 PRRT because of worries about travelling to X from home...

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

● Rx change ● No change ● N/a



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.

I have monthly lanreotide injections done by a practice nurse at the local doctors surgery (2min walk away) the surgery would not let me attend...so I have had to get my mum (who I don't live with) to give me the injection...

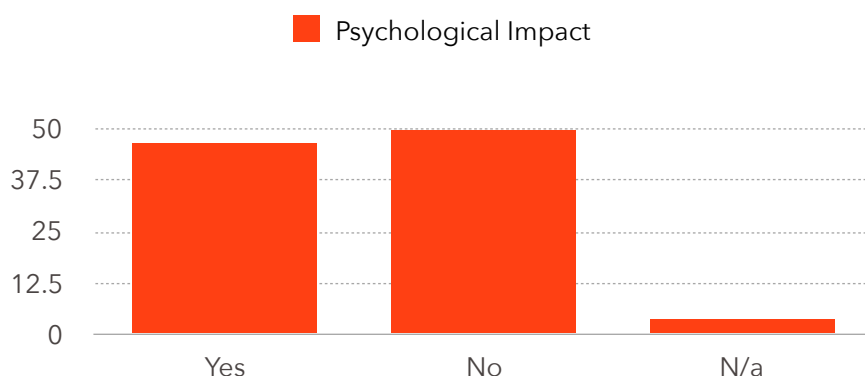
A proportion of patients also expressed frustration at a lack of GP accessibility, blood tests and obtaining medication.

Impossible to get my Doctor to repeat my prescription and cannot get on NHS app...it sends me to my Doctors and they send me back on it ...

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

Psychosocial impact

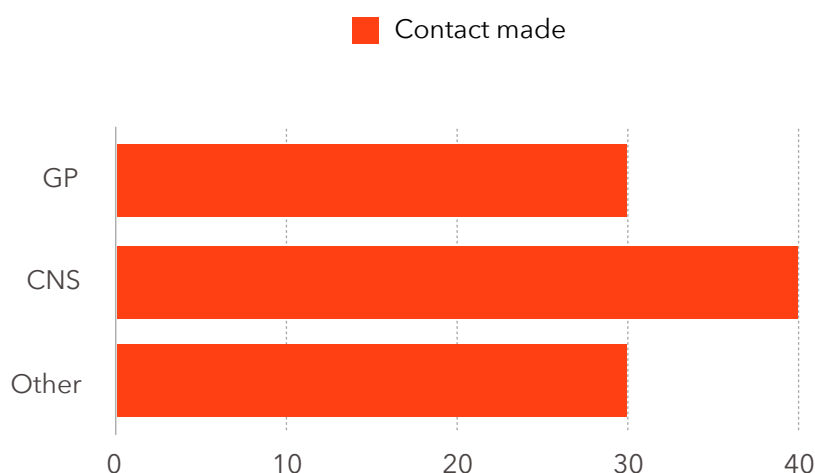
The psychosocial impact of the Covid-19 pandemic is quite significant amongst survey respondents, with just under 50% reporting psychological symptoms.



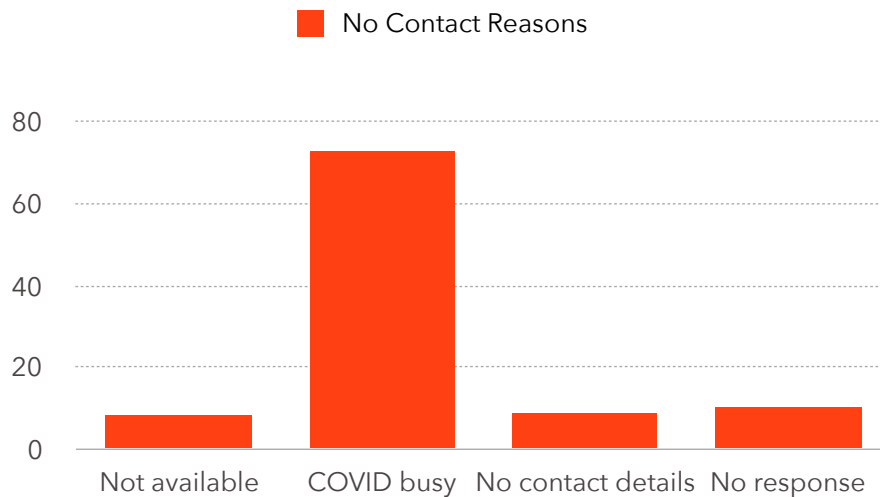
Increased anxiety and frustration induced by the pandemic and it's knock on effect in accessing healthcare resources is notable.

Anxiety. Covid-19. Tumour progression. Not being able to discuss these with support staff. . .

From responses, 66% of patients felt they had access to advice and support from their healthcare team during this time, and this was primarily from specialist nurses (40%) or from primary care (30%).



Just over a third of respondents did not receive any help from their specialist team, health care professional or other health care services, however, the primary reason given for this was that respondents did not make contact because they felt staff would be too busy dealing with COVID19. Identifiable concerns are that some respondents reported that they did not have the contact information they required, their point of contact was not available or they received no response.



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 usually seen less frequently.

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.

"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."

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.