The impact of COVID-19 on lung cancer care: views from lung cancer specialist nurses

Introduction

Lung Cancer Nursing UK (LCNUK) – formerly the National Lung Cancer Forum for Nurses – was established in 1998 to provide networking and support to nurses specialising in the care of people with lung cancer. We support our members by sharing knowledge and best practice on clinical areas, and by providing a voice for lung cancer nurse specialists on strategic issues associated with lung cancer and service delivery.

COVID-19 has had a profound effect on all aspects of healthcare delivery, including on cancer services. The particular risks of COVID-19 for lung cancer patients have necessitated significant changes to the way healthcare teams are operating to treat and care for patients.

Clinical nurse specialists (CNSs) are a crucial support to, and advocates for, lung cancer patients from diagnosis throughout their cancer journey. In July 2020, Lung Cancer Nursing UK shared an online survey with our members to understand how the pandemic was affecting their work and the care they felt able to provide to patients.

This short report sets out the key findings from the survey, along with recommendations for policymakers and system leaders. We hope the findings and recommendations will be valuable to NHS leaders at all levels, as cancer teams across the UK work together to quickly restore services for the lung cancer patients who need them, while embedding positive innovations learned through the pandemic.

Throughout this time, we will be doing our utmost to support our members to care for themselves, as well as caring for patients.

For more information about this survey, or the work of LCNUK more broadly, please contact info@lcnuk.org.

Jackie Fenemore
Chair of the LCNUK Committee

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Recommendations

1. LCNSs to work closely with acute oncology teams/support for reviewing patients with suspected lung cancer in A&E. More collaborative working support/education

2. LCNSs must not be redeployed in the event of a second wave of COVID-19. Uncertainty due to reduced treatment options/lack of medical support staff. Patients more isolated. Increase in telephone work if patients are not face-to-face

3. More specific LCNS training in breaking bad news/remote support via electronic/telephone communications and better psychological support for LCNSs eg mindfulness/anxiety management etc to recognise increased emotional impact on CNSs

4. Better access to clinical supervision for CNSs

5. More awareness across the UK for earlier diagnosis of lung cancer/crossover symptoms/timely investigations/red flags information on when to seek support/assessment/medical help

6. Work to understand patient perspective and preferences on the impact of COVID-19 re telephone assessment/face-to-face attendance for review

7. Publish finding of survey and subsequent audit on LCNUK website

8. Write guidelines with recommendations for commissioners of services re:
    - LCNS provision/no redeployment/ resources for training re remote consultations
    - Better links with A&E/emergency presentations
    - Better communication between primary and secondary care

Methodology

The online survey was shared by LCNUK with their members and open for responses from 22 May to 17 July 2020. The survey comprised of nine questions (please see Appendix for the full list) covering important aspects of service delivery and clinical care, including:

- Deployment of the workforce (both CNSs themselves and their teams) during the pandemic and the impact on services
- Whether and to what extent video and telephone consultations replaced face-to-face hospital appointments and, if so, to what proportion
- Whether new patients were still being seen by CNSs, and if the numbers of patients being seen changed
- How many patients were being referred through the emergency route
- What the most challenging impacts of the pandemic have been, for nurses and their teams and also for patients

51 nurses responded to the survey.

The majority of the questions were closed questions, with nurses selecting specific answers or ranges. However, the last two questions on the effects of COVID-19 for teams and patients were open questions. The analysis that follows makes clear where we are drawing from either quantitative or qualitative data.

Key findings

- More than half of the CNS who responded (28, 55%) have been themselves, or had team members, redeployed or unable to work as a result of COVID-19
  - Of these, 21 of the 28 said that this equated to 25% or more of their service
- Consultations have shifted from face-to-face to virtual, due to the pandemic
  - Nearly nine in ten respondents (45, 88%) have increased the number of appointments they are doing virtually
  - Just two respondents (4%) said the number of virtual appointments they were doing had stayed the same
- The majority of CNSs are now doing most of their consultations virtually
  - Nearly two thirds of respondents (33, 65%) are now doing between 75% and all of their consultations virtually
  - A further quarter (12, 24%) are doing between half and 75% of consultations virtually
- The majority of CNSs responding to the survey are seeing lower numbers of new patients than before the start of the pandemic
  - 31 respondents (61%) said they would normally expect to see more new patients
  - 20 (39%) chose the same range for numbers of patients they'd usually expect to see
- The majority of CNSs responding to the survey estimated that a greater proportion of referrals are now coming through the emergency route (prior to COVID-19, around 32% of all lung cancer patients were diagnosed as an emergency):
  - 29 respondents (57%) estimated that more than 32% of their patients were referred as an emergency
  - 25 respondents (49%) estimated that 50% or more of their referrals were via the emergency route
  - 12 respondents (24%) estimated that 75% or more of their referrals were via the emergency route
- Lung CNSs and their teams are finding the following effects of COVID-19 difficult to deal with:
  - 35 respondents (69%) raised difficulties in communicating with patients digitally rather than face-to-face, especially in terms of breaking bad news
  - 23 respondents (45%) highlighted the impact of a redeployed / reduced team and increased workload
  - 14 (27%) had concerns around maintaining service safety and/or performance
- Lung CNSs also identified significant difficult impact for patients:
  - More than half of the responding lung CNSs (27, 54%) raised concerns around treatments being changed, delayed or unavailable as a result of the pandemic
  - Fear was a common theme (22 respondents, 44%) including fear of going out or being in hospital
  - Isolation was another common theme (27 respondents, 54%) including patients being lonely or isolated from family while shielding or not being able to have visitors in hospital
  - A third of respondents (16, 32%) raised the impact on patients of receiving bad news virtually

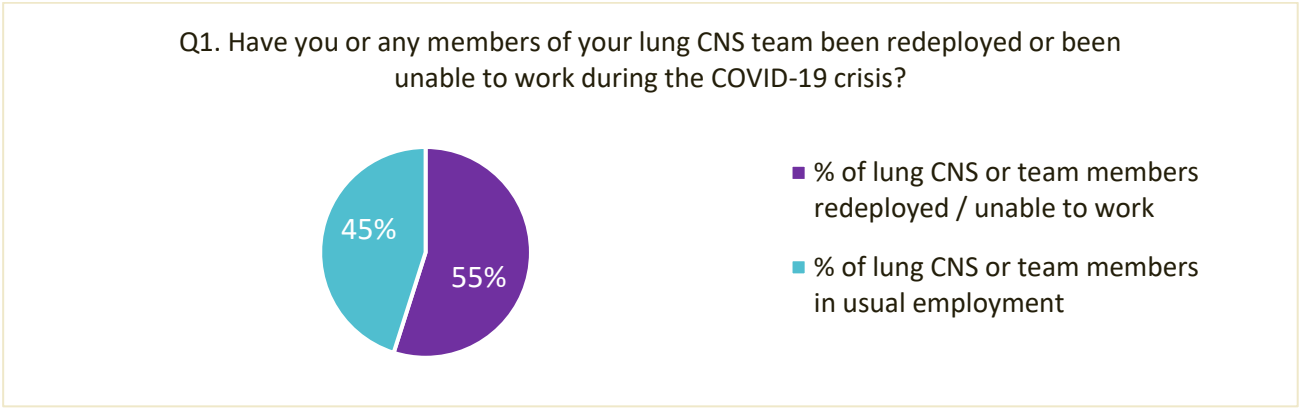
Workforce redeployment and absences

The survey showed that the majority of lung cancer CNS had themselves been, or had team members, redeployed or unable to work due to COVID-19.

As the health service struggled to cope with the impact of COVID-19, many staff were redeployed from their normal roles to other parts of the NHS. Others were unable to work because they were having to shield, either because they have a condition putting them at higher risk of infection or family members who are clinically vulnerable.

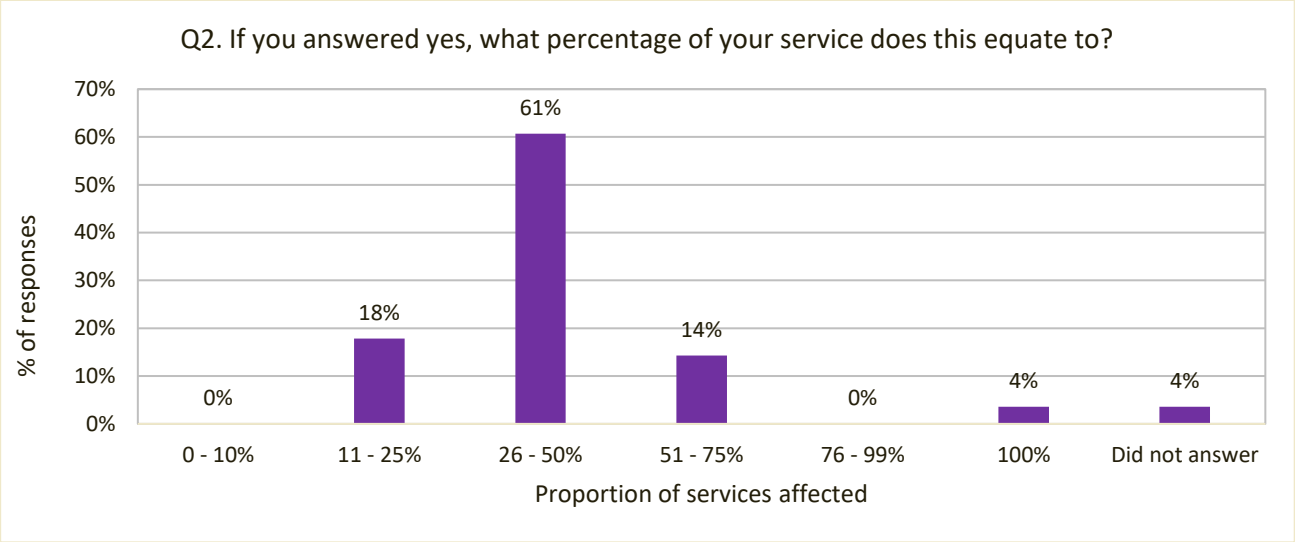
As set out in Figure 1, more than half (28, 55%) of LCNSs who responded to the survey said they, or a member of their team, had been redeployed or unable to work during COVID-19. For those who stated they had been redeployed, a follow up question was asked to understand the extent to which they had been stood down.

Figure 1: Proportion of lung CNSs who had themselves, or had team members, redeployed or unable to work



For most of the teams, redeployment or absence affected a significant proportion of their service (Figure 2). Of those who answered 'yes', the majority (17, 61%) said this represented between a quarter and half of their service. A further 4 (15%) said it equated to more than half. One respondent (4%) answered 100%.

Figure 2: Proportion of lung CNSs who had themselves, or had team members, redeployed or unable to work



Redeployments and absences has led to increased workloads. A number of nurses commented that workforce changes – or indeed the expectation of them – were increasing stress and anxiety levels for the team:

"Stressful time..lots of unrest early on and redeployment. A few staff were deemed high risk and therefore based in the office after risk assessment. Some CNS had to go on COVID wards too."

"We have as a team also felt the need to try to support our consultant colleagues by taking on increased responsibilities or decisions to reduce the pressure on them as they have been working clinically both day and night."

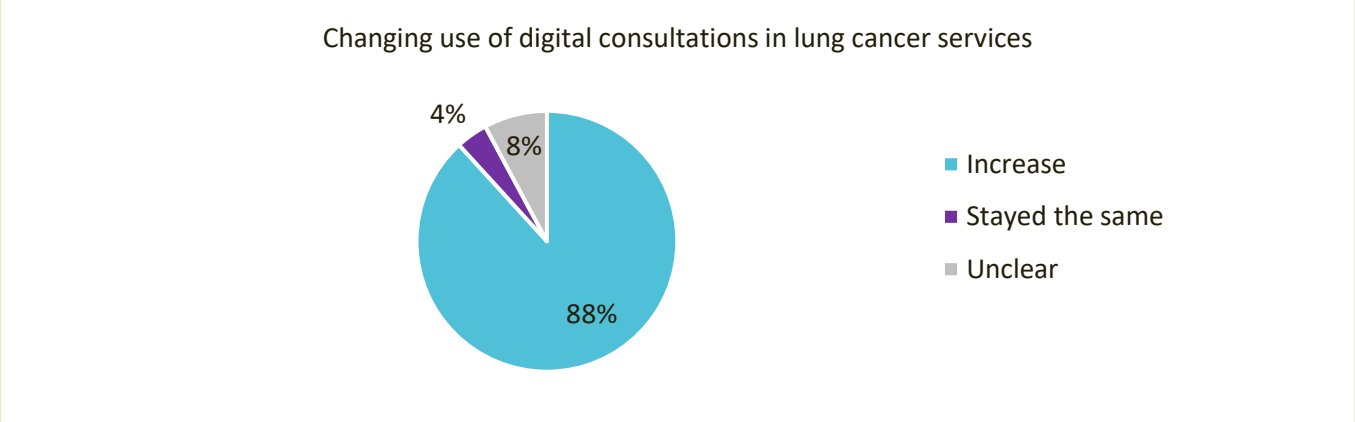
The shift to virtual consultations

As the pandemic spread, the NHS was asked to increase the use of virtual consultations. NHS England issued guidance for patient management, including asking hospitals to consider specific use of specialist nurses.[1]

The survey asked CNSs what proportion of consultations were taking place virtually during and before the pandemic. **The survey found that the majority of lung CNSs are now doing most of their consultations via electronic means (video or telephone).**

Nearly nine in ten survey respondents (45, 88%) reported an increase in the proportion of consultations that are being done digitally, compared to before the pandemic (Figure 3). Just two respondents indicated that the proportion had stayed the same. Four responses were unclear as they had not answered both questions needed for the calculation.

Figure 3: Change in use of virtual consultations



The shift has been substantial. Two thirds of respondents (33, 65%) said they were now doing between 75% and all of their consultations digitally. A further quarter (12, 24%) said they were doing between 50 – 75% (Figure 4).

What is not clear is the impact on lung cancer patients of the shift from face-to-face to virtual consultations. Respondents to the survey raised a number of concerns about the use of virtual consultations. These included:

- The impact and distress caused by having to break bad news or have difficult conversations by phone
- Difficulties with hearing patients in virtual consultations
- Inability to pick up on non-verbal cues
- Patients feeling frightened or isolated, especially when unable to see a familiar face
- Not being able to provide sufficient emotional support or comfort through touch

"Very reduced patient contact and assessing over the phone, not being able to pick up on non verbal cues."

"The patients have also been terrified so the telephone conversations have been incredibly difficult… there has been an overwhelming sadness in a lot of the conversations."

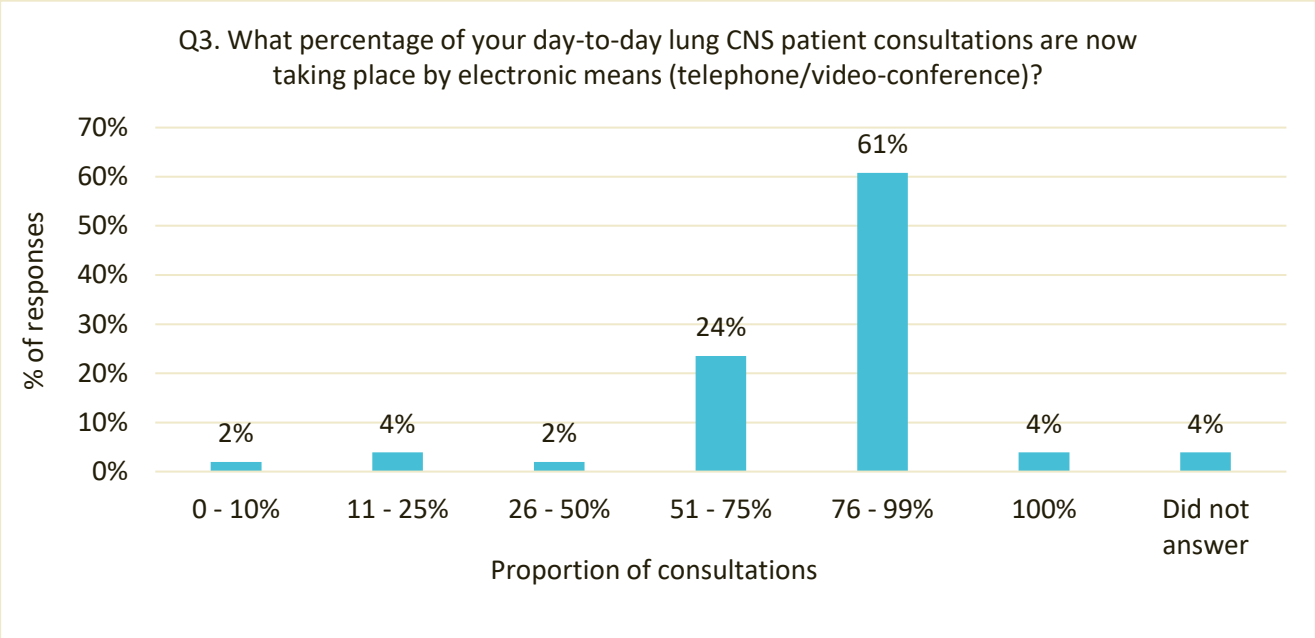
[1] NHS England, *Clinical guide for the management of remote consultations and remote working in secondary care during the coronavirus pandemic*, 27 March 2020

Even where face-to-face consultations were happening, social distancing is making it harder for lung CNSs to offer the comfort that they usually would:

> *"Not also being able to comfort patients and relatives in face to face consultations because we are not able to touch / hug / shake / hold a hand. Very hard having someone crying in front of you and not using touch."*

Further research is needed to fully understand how virtual consultations are working, both from a health professional perspective and from patients' points of view. This should include differences between phone and video calls in terms of quality and experience of care.

Figure 4: Proportion of patient consultations now taking place virtually



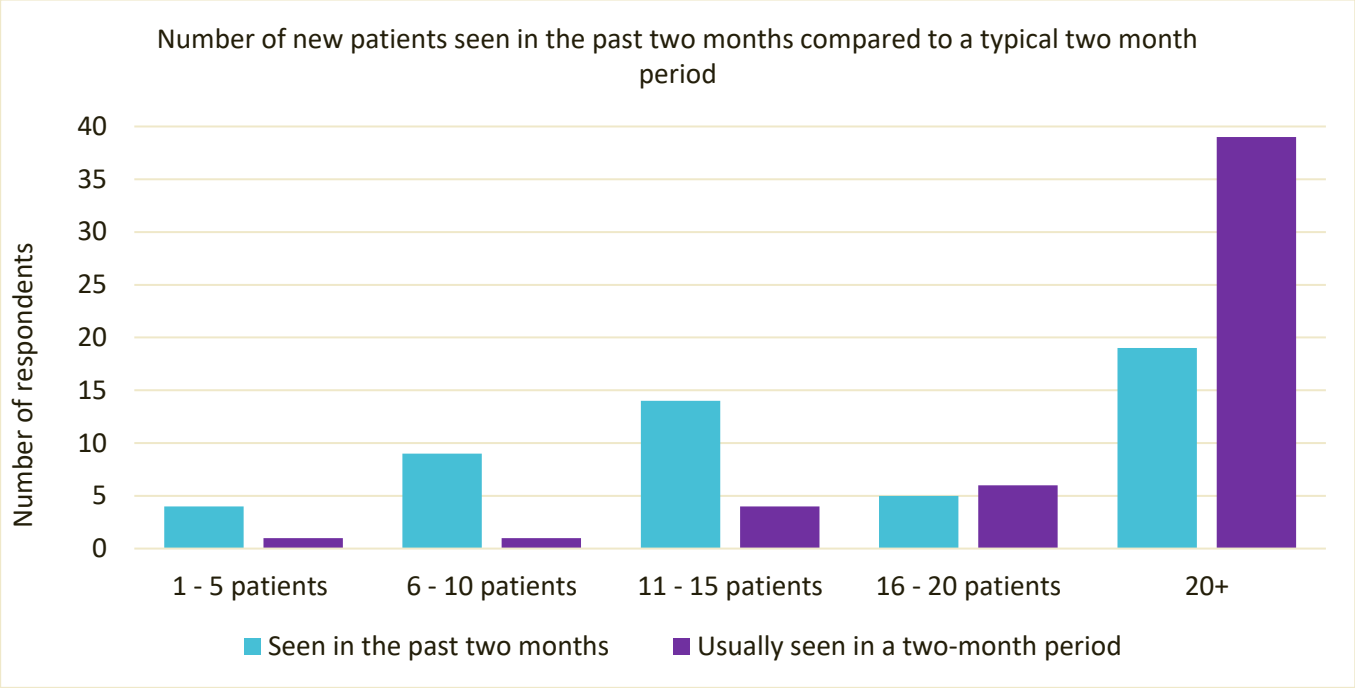
Where are the new lung cancer patients?

The survey asked lung cancer CNSs how many new patients they had assessed and supported over the last two months, and how many they would normally expect to see in this timeframe.

All respondents reported seeing new patients in the last two months. 19 respondents (37%) had seen more than 20 new patients in the last two months (Figure 5).

However, **numbers of new patients are not as high as usual**. Nearly twice as many lung cancer CNSs (39, 76%) would have expected to see more than 20 patients in a 'typical' two-month period as did so. Overall, six in ten respondents (31, 61%) said that they would normally expect to have more new patients. The remaining 20 (39%) thought the number of new patients seen was in the same range.

Figure 5: Comparison of new patients seen in past two months vs typical two month period



This is a concern as lung cancer can be an aggressive cancer, and earlier diagnosis is essential in being able to give active treatment and maximise chances of survival. From the early days of the pandemic, there have been concerns that patients may be delaying in seeking help for fear of catching the virus while seeing the GP or attending hospital. These concerns were echoed by members' comments:

"New lung cancer clinic referrals [have] gone down drastically."

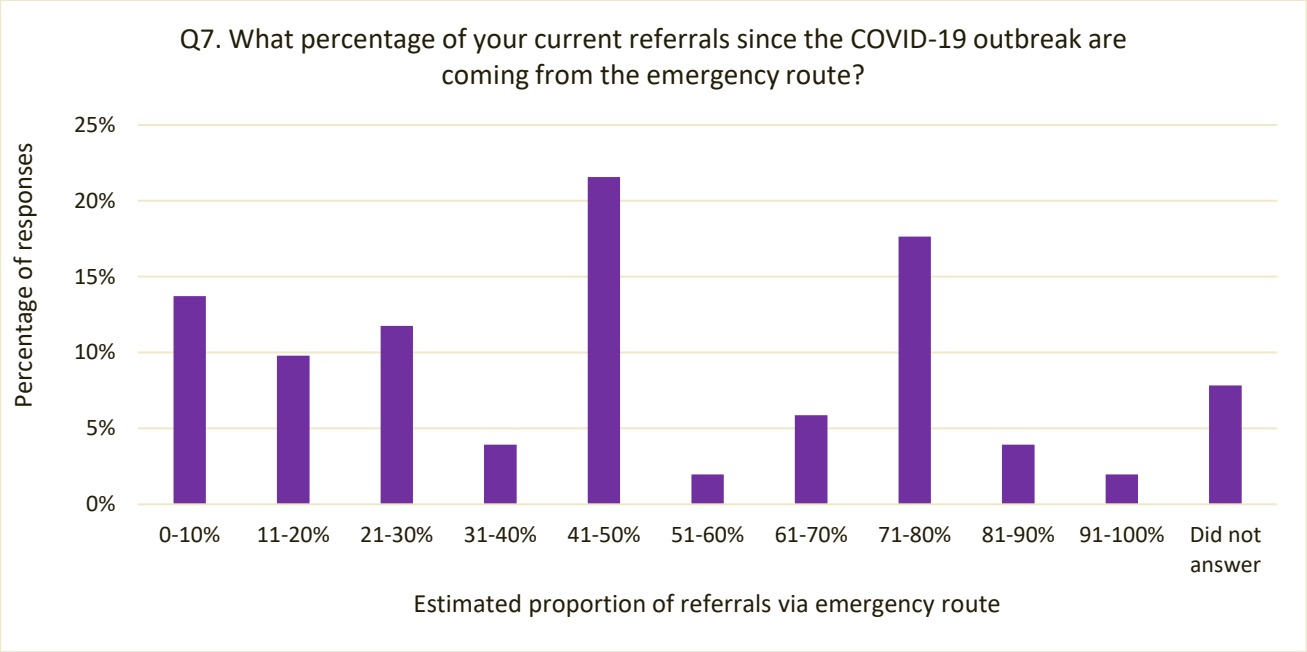
"We are now receiving large numbers of referrals with stage 4 disease. These patients have been too scared to attend the GP or hospital with obvious symptoms with regards to the COVID situation."

"We are starting to see patients who have ignored symptoms due to a fear of coming to the hospital and am sure this will continue."

Referrals via the emergency route

Prior to COVID-19, around 32% of all lung cancer patients were diagnosed as an emergency presentation.[2] More than half of respondents to this survey (29, 57%) estimated that more than 32% of their patients were now being referred as an emergency. In addition, 49% of respondents estimated than half or more of their referrals came via this route, with a quarter estimating this number is more than three quarters of all patients (Figure 6):

Figure 6: Proportion of current referrals via the emergency route



Nurses commented:

> *"I don't believe the emergency route patients have peaked yet and think we are due large numbers in the coming months."*

> *"[I'm] worried about the number of late presentations once the lockdown eases up."*

These data are concerning, especially when taken together with the findings about lower numbers of new patients. It is essential that efforts are made to:

- Remind people of the symptoms of lung cancer and that they should continue to seek help early from their GP
- Ensure that patients referred are still able to get the diagnostic tests needed to confirm a diagnosis of lung cancer
- Ensure that patients are able to rapidly begin treatment, under the care of a specialist multi-disciplinary team

[2] National Cancer Registration and Analysis Service, *Routes to Diagnosis*, 2016

COVID-19's most difficult challenges for lung CNSs' and their teams

Healthcare professionals have been on the frontline of the response to COVID-19, doing their utmost to keep cancer services going while adapting to new ways of working with limited resources. We asked our members what they felt the most difficult impacts of the COVID-19 pandemic were for them and their teams.

From the unprompted free text responses, a number of themes emerged:

- **Communication difficulties – both within teams and with patients.** Lung CNSs are having to do less face-to-face and more phone or video appointments. This has meant rapid adoption of, and adaption to using new technologies. 35 respondents (69%) commented found it difficult to be communicating with patients digitally rather than face-to-face, especially in terms of breaking bad news.

"Having to break bad news and have difficult conversations over the telephone instead of face to face. Missing the human interactions and non verbal cues has a big impact on the empathy and compassion able to give."

"We are working differently, more phone calls, less face to face. The team are working with new technology with little or no support."

- **Increased workload,** resulting from a redeployed or reduced team or changes to services was another major impact for nurses and teams, cited by 23 respondents (45%).

"Increased workload while a colleague who is shielding didn't have IT access initially... Increased workload due to longer pathway for pre-diagnosis patients and delays in investigations due to reduced service and staff illness. Increased need to support patients who are affected by reduction in other supportive services."

- **Maintaining service safety and/or performance** was a concern for a quarter (14, 27%) of respondents.

"Managing clinic attendances ensuring the safest pathway for patients and ensuring staff safety as much as possible…making sure staff are feeling safe at work."

"Maintaining normal pathways when services have ceased or moved to other sites."

"For me as an oncology nurse it has been difficult not being able to offer palliative chemotherapy to [patients with] advanced disease."

- **Fear and anxiety** for themselves, their families and colleagues has understandably also been an issue for lung CNSs:

"The initial fear of coming to work before we knew the real nature / dangers of the pandemic. The worries we carried for our patients who were nearly all at increased risk. The anxiety and fear for our own families."

"Staff are worried for their loved ones and taking home the virus."

"As we work closely with the respiratory team there has been concern for our medical colleagues and they have been on the front line and caring for COVID patients on the cohort wards."

COVID-19's most difficult challenges for patients – lung CNSs' views

We also asked our members what they felt the most difficult impacts of the COVID-19 pandemic were for patients. Again, from unprompted free text responses, a number of important themes emerged:

- **Changes to diagnostic and treatment pathways and their implications for patient outcomes –** more than half of the responding lung CNSs (27, 54%) raised concerns around treatments being changed, delayed or unavailable as a result of the pandemic

"For patients going through the diagnostic pathway it has been the cancelling of biopsy lists, EBUS lists and surgery."

"Surgery has basically been stopped within our trust due to a lack of surgeons and capacity issues."

"Patients at high risk having treatments deferred or discontinued."

"Accepting that chemotherapy is high risk and it not being able to be given – a feeling described as 'abandonment'."

- **Fear** was a common theme, raised by 22 lung CNSs (44% of respondents). This included fear of going out of the home and contracting the virus, or of picking up infection while in hospital for treatment.

"The fear of COVID has been greater than the fear of their cancer."

"Patients have been frightened and concerned about their anti-cancer treatment in light of the pandemic and also anxious about having to come into the hospital."

"Lack of certainty, shielding and fear of leaving the house."

- **Isolation** was another common theme, raised by 27 respondents (54%). This including patients being lonely or isolated from family while shielding and so dealing with their lung cancer alone. Nurses also highlighted the isolation experienced by patients not being able to have visitors in hospital, and the particular distress when patients are nearing the end of life.

"Shielding and isolation causing emotional distress particularly when dealing with bad news."

"People are isolated and lonely and they feel neglected."

"May never see loved ones again if admitted to hospital."

- **Lack of face-to-face support**, without being able to offer adequate physical or emotional comfort was highlighted by a third of respondents (16, 32%).

"Diagnosis given on the phone – difficulties with hearing and no physical emotional support being able to be given."

"The contact with us, face to face, not being able to comfort patients, barriers of face masks and social distancing, between us and them and them and their own family that they need for support at this challenging, difficult and emotional time."

Appendix: full list of survey questions and responses

1. Have you or any members of your lung CNS team been redeployed or been unable to work during the COVID-19 crisis

2. If you answered yes, what percentage of your service does this equate to?

3. What percentage of your day-to-day lung CNS patient consultations are now taking place by electronic means (telephone/video-conference)?

4. What percentage of your day-to-day lung CNS patient consultations used to take place by electronic means?

5. How many NEW patients with lung cancer have you assessed and supported in the last two months?

6. How many NEW patients with lung cancer would you usually assess and support in a two month period?

7. What percentage of your current referrals since the COVID-19 outbreak are coming from the emergency route presentation

8. What do you think has been the most difficult impact of the COVID-19 pandemic on yourself and your team?

9. What do you think has been the most difficult impact of the COVID-19 pandemic on your patients?