LUNG CANCER NURSING UK

CNS provision during COVID-19

Findings of a survey of lung cancer specialist nurses

August 2020

Project objective

- 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 has necessitated significant changes to the way healthcare teams are operating to treat and care for patients
- Lung cancer clinical nurse specialists (CNSs) are a crucial support to, and advocates for, lung cancer patients from diagnosis throughout their cancer journey
- Lung Cancer Nursing UK wanted to understand how the pandemic was affecting working patterns for lung CNSs
- In July 2020, Lung Cancer Nursing UK shared an online survey with its members
- The slides that follow set out key findings from the survey

Methodology

- The online survey was open from 22 May to 17 July 2020 and comprised of nine questions :
  - Whether lung CNSs had been redeployed or unable to work during COVID-19
  - If so, what proportion of the service this equated to
  - What percentage of day-to-day consultations were taking place digitally, by video or telephone
  - What percentage of day-to-day consultations would normally take place digitally
  - How many new patients had been assessed and supported in the last two months
  - How many new patients would normally be assessed and supported in a two month period
  - What percentage of current referrals since COVID-19 were coming as an emergency presentation
  - What has been the most difficult impact of COVID-19 for the CNS and team
  - What has been the most difficult impact of COVID-19 for patients
- 51 lung CNSs completed the survey

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 this equated to 25% or more of their service
- COVID-19 has meant shifting consultations from face-to-face appointments to digital
  - Nearly nine in ten respondents (45, 88%) have seen an increase in appointments done this way
  - Just two respondents (4%) said this had stayed the same
- The majority of CNS are now doing most of their consultations via electronic means
  - Nearly two thirds of respondents (33, 65%) were now doing between 75% and all of their consultations digitally
  - A further quarter (12, 24%) were doing between half and 75% of consultations digitally
- New patient numbers are down
  - 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

Key findings

- Prior to COVID-19, around 32% of all lung cancer patients were diagnosed as an emergency. The majority of CNSs responding to the survey estimated that a greater proportion of referrals are now coming through the emergency route:
  - 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:
  - Communicating with patients virtually, rather than face-to-face, especially in breaking bad news
  - The impact of a redeployed / reduced team and increased workload
  - Maintaining service safety and / or performance, including late presentation and delayed referrals
- Lung CNSs are concerned about the following impacts for patients:
  - Treatments being changed, delayed or unavailable
  - Levels of fear, including fear of going out or having to go to hospital
  - Isolation and loneliness, both at home coping with diagnosis or in hospital without family visitors

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. 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

Recommendations

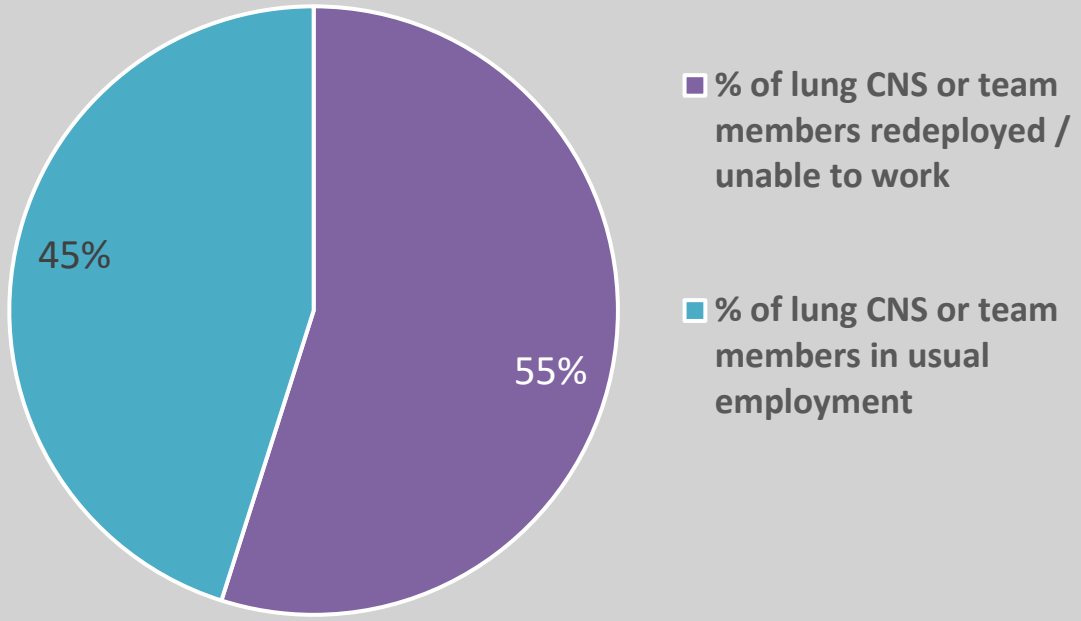
5. More awareness across the UK for earlier diagnosis of lung cancer/crossover symptoms/timely investigations/red flags information on when to seek support/assessment/medical help
6. Work to understand patient perspective and preferences on the impact of COVID-19 re telephone assessment/face-to-face 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

More than half of CNSs have been themselves or had team members redeployed / unable to work due to COVID-19

Just over half (28, 55%) of the CNSs responded to say that either they or members of their team had either been redeployed or were unable to work as a result of COVID-19

"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."

Q1. Have you or any members of your lung CNS team been redeployed or been unable to work during the COVID-19 crisis?



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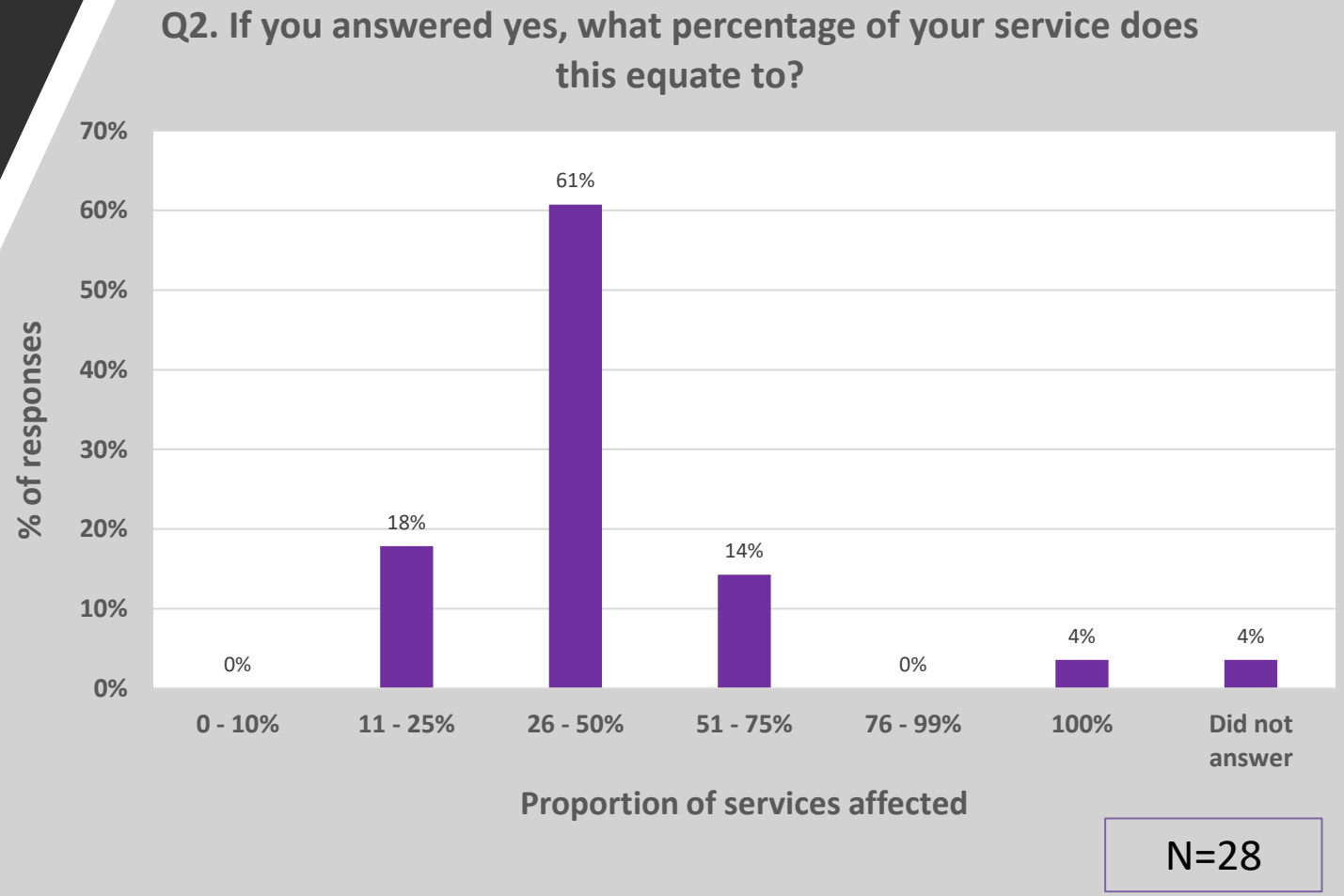
This equates to a significant proportion of the service for most of the teams affected

Of the 28 respondents who said that either they or team members had been redeployed or were unable to work as a result of COVID-19:

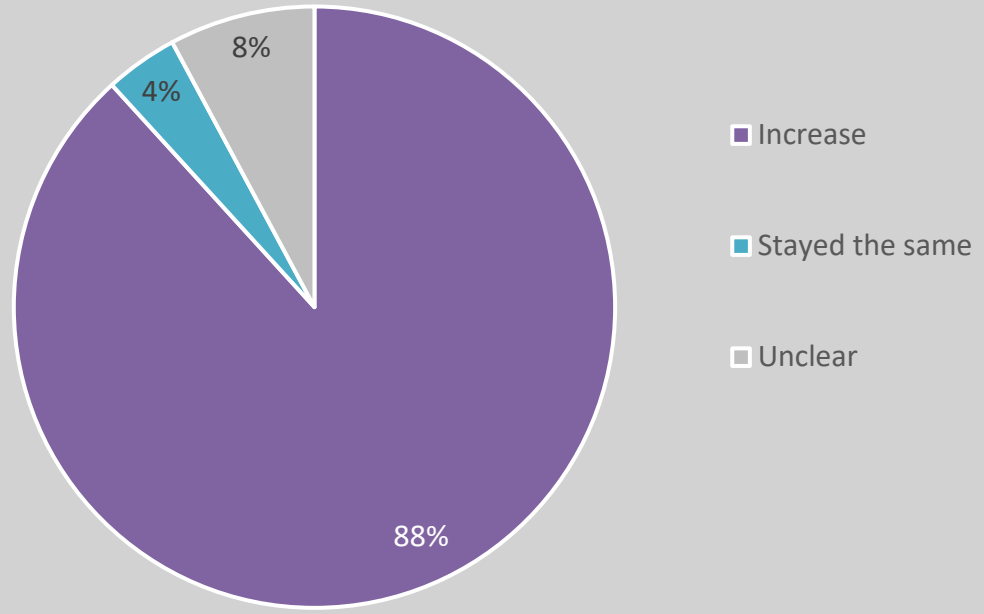
- 5 (18%) said this equated to between 11-25% of their service
- 17 (61%) said this equated to 25% -50% of their service
- 4 (15%) said this equated to more than half of their service



COVID-19 has meant shifting face-to-face to digital appointments

The vast majority (88%) of respondents had seen an increase in the proportion of consultations done digitally, compared to before the pandemic

- 2 respondents indicated it had stayed the same
- 4 responses were unclear because they did not answer either Q3 or Q4



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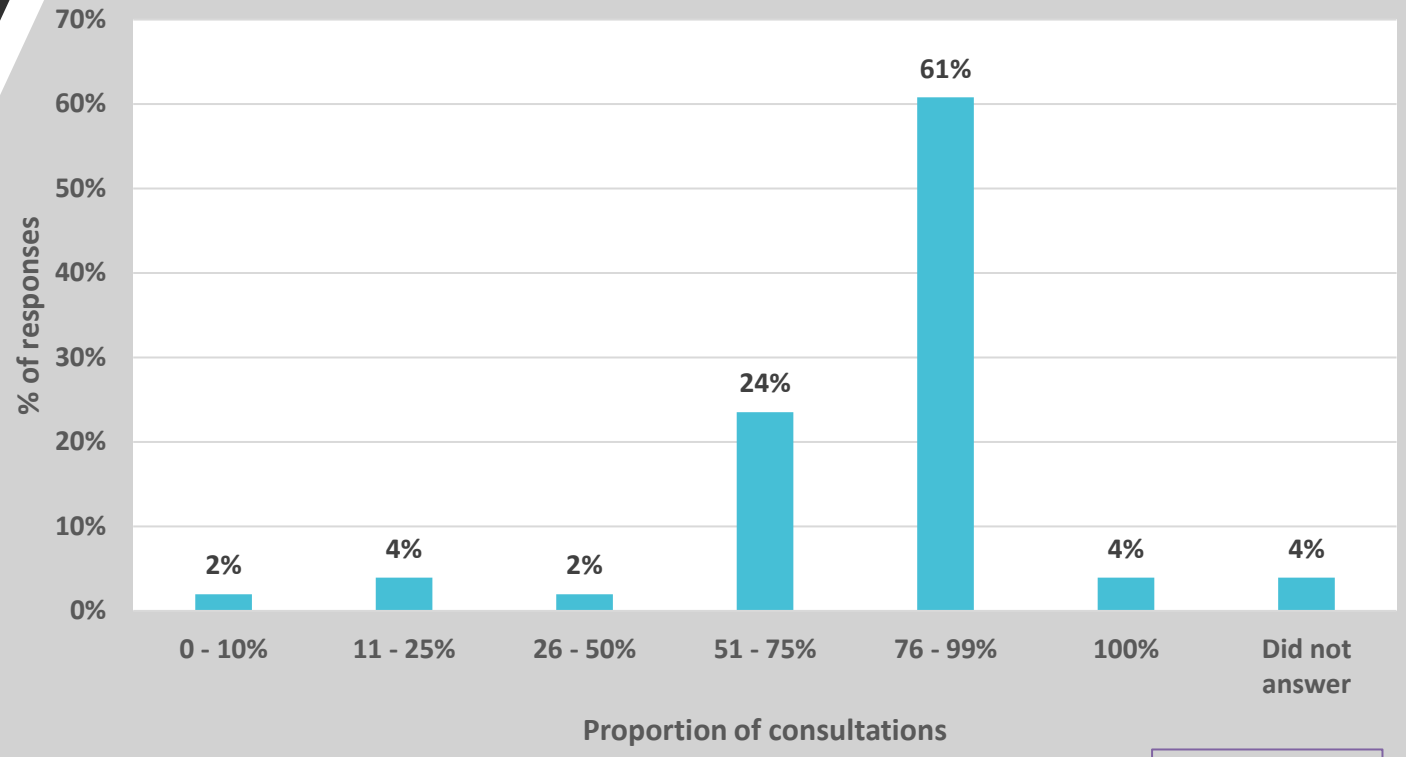
The majority of consultations with CNSs have been taking place by electronic means

The majority of respondents are doing most of their consultations via telephone or video

- Nearly two thirds of respondents (33, 65%) were now doing between 75% and all of their consultations digitally
- A further quarter (12, 24%) were doing between half and 75% of consultations digitally

"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."

Q3. What percentage of your day-to-day lung CNS patient consultations are now taking place by electronic means (telephone/video-conference)?



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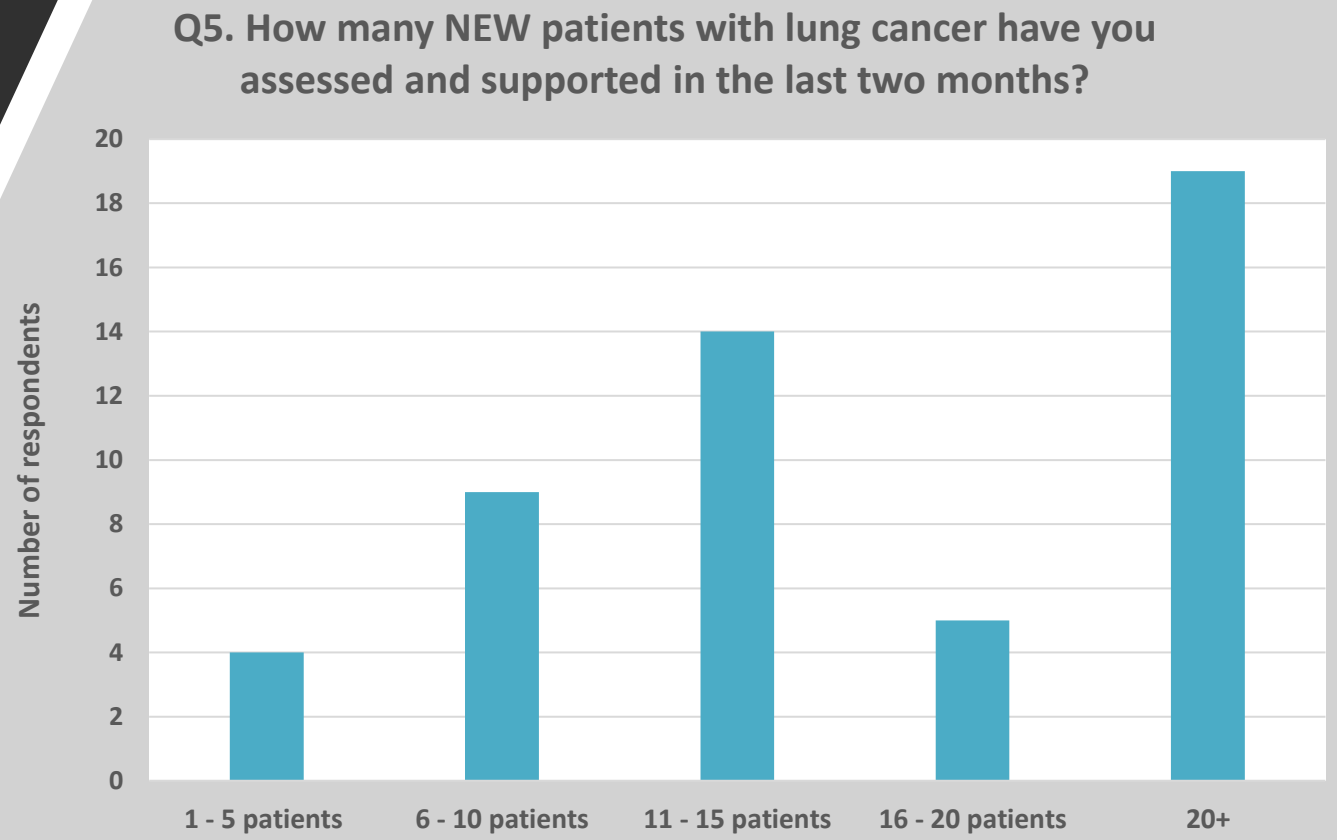
New lung cancer patients are still coming through

All respondents had seen new lung cancer patients during the past two months

- Four (8%) had seen between one and five new patients
- Nine (28%) had seen between six and ten new patients
- 14 (27%) had seen between 11 and 15 new patients
- Five (10%) had seen between 16 and 20 new patients
- 19 (37%) had seen more than 20 new patients



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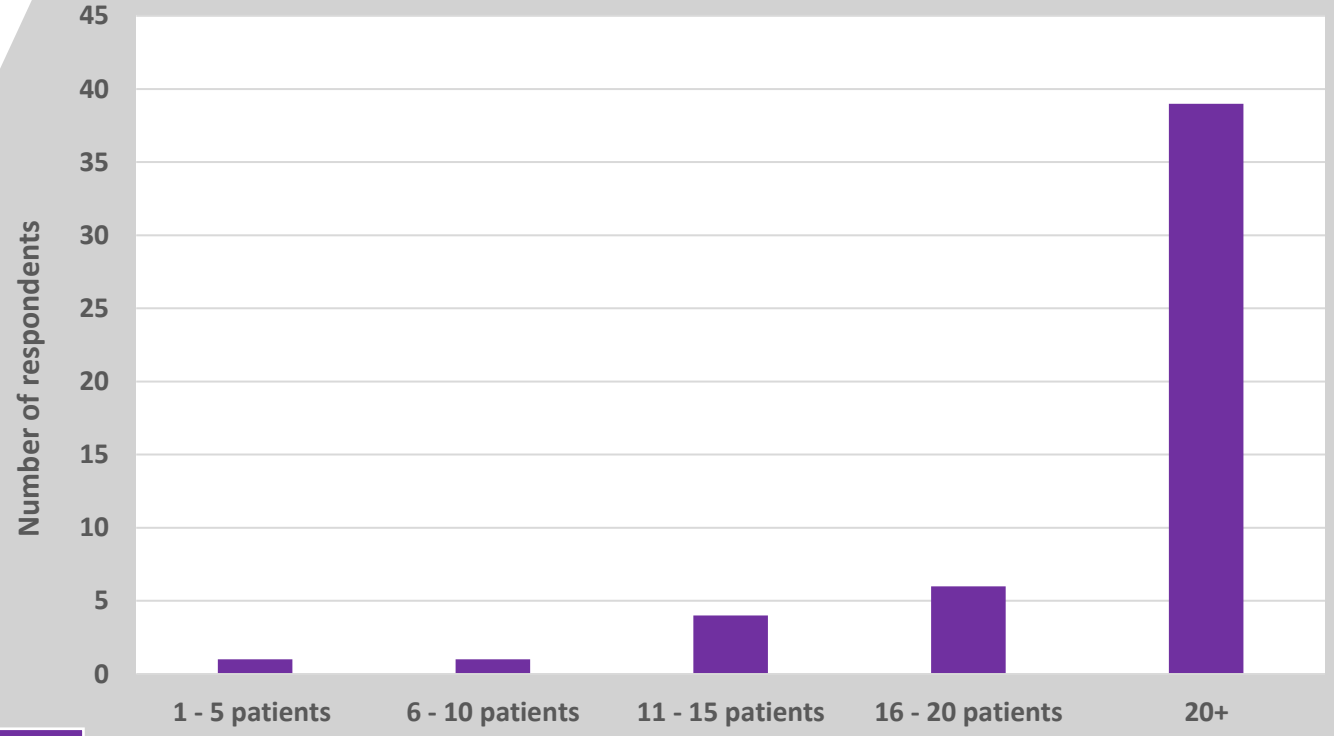
However, numbers of new patients are not as high as usual

Over a normal two month period:

- One respondent (2%) would expect to see between one and five new patients
- One respondent (2%) would expect to see between six and ten new patients
- Four (8%) would expect to see between 11 and 15 new patients
- Six (12%) had seen between 16 and 20 new patients
- 39 (76%) would expect to see more than 20 new patients

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

Q6. How many NEW patients with lung cancer would you usually assess and support in a two month period?



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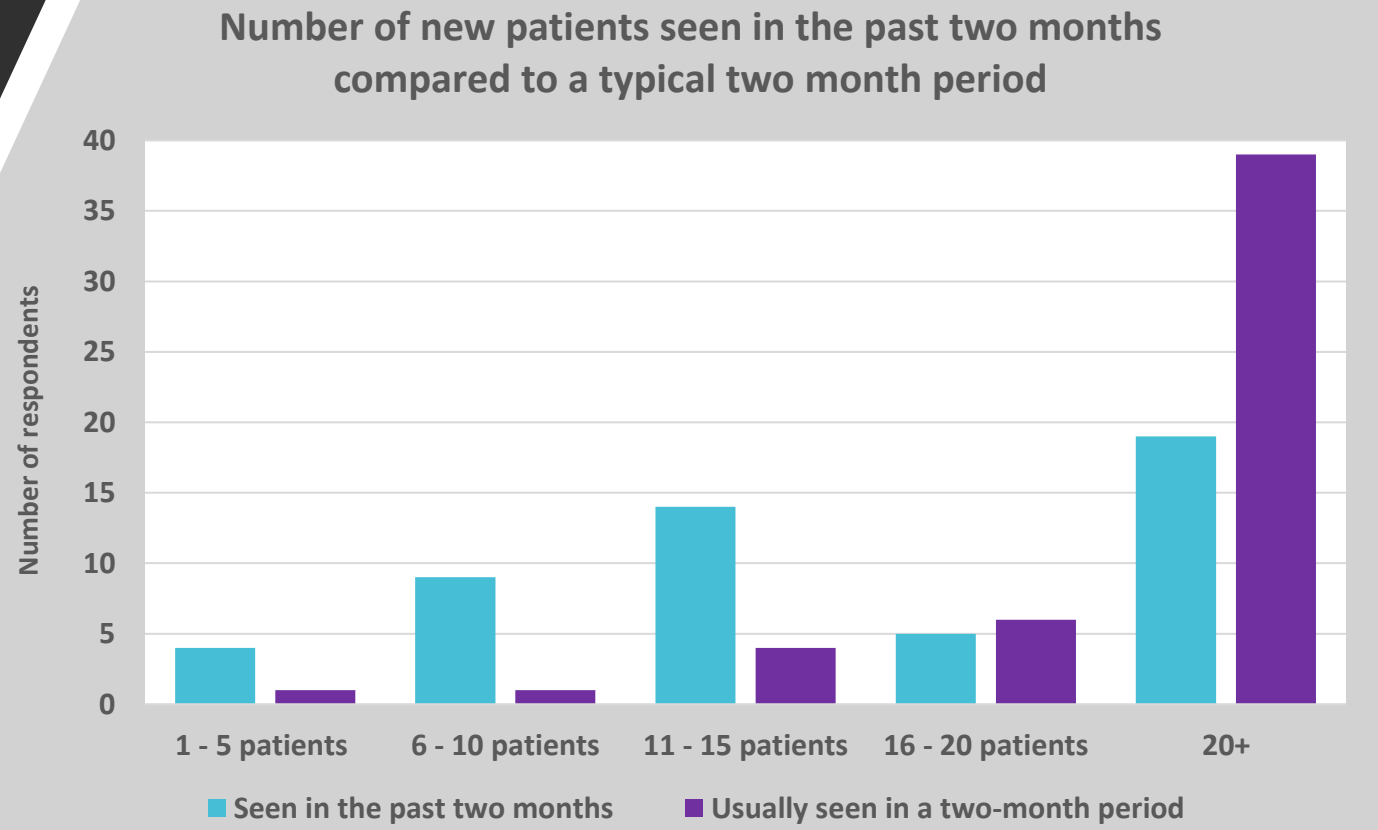
New patient numbers are down

New patient numbers are down, compared to usual numbers seen

- 31 respondents (61%) said they would usually expect to see more patients
- 20 respondents (39%) chose the same number range
- No respondents said they would expect to see fewer patients

"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."



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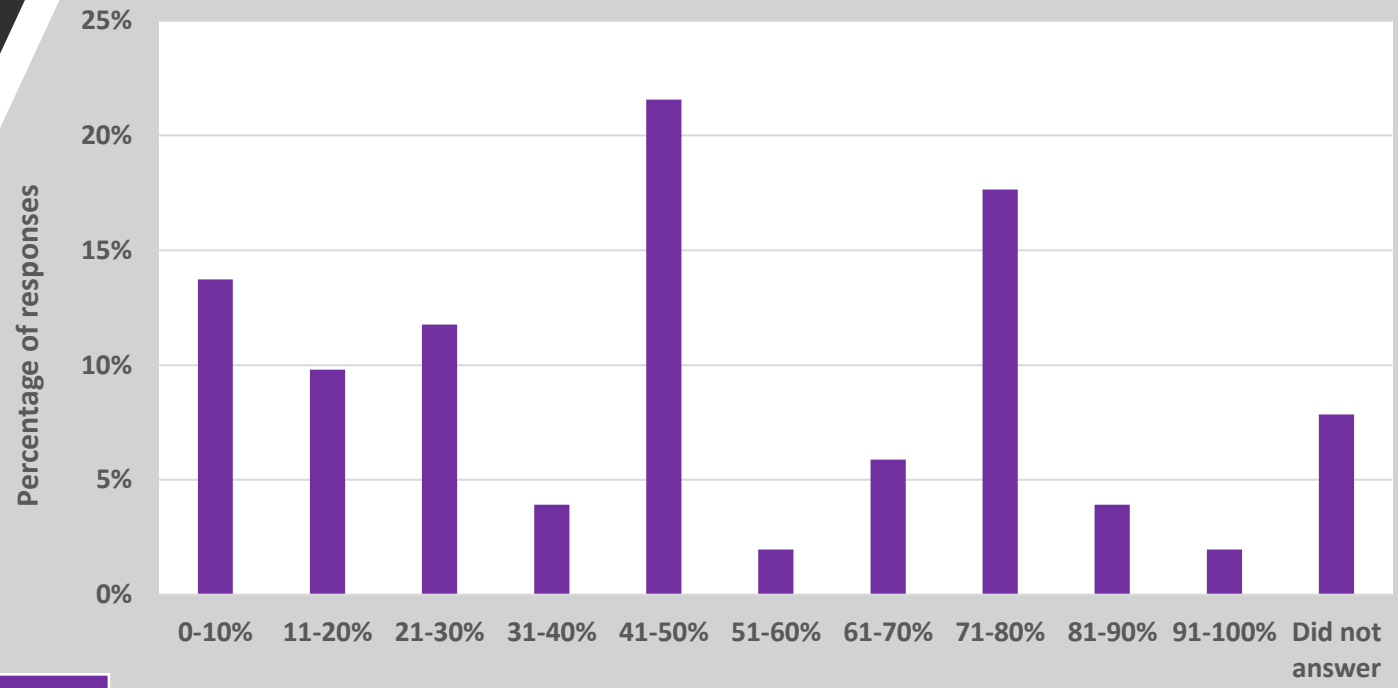
More patients are being referred as an emergency than prior to COVID-19

Prior to COVID-19, around 32% of all lung cancer patients were diagnosed as an emergency presentation[1]

- 29 respondents (57%) estimated that more than 32% of their patients were referred as an emergency
- 25 respondents (49%) estimated that half or more of their referrals were via the emergency route
- 12 respondents (24%) estimated that three quarters or more of their referrals were via the emergency route

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

Q7. What percentage of your current referrals since the COVID-19 outbreak are coming from the emergency route?



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1. NCRAS, Routes to Diagnosis, 2016

Lung CNSs identified a range of difficult challenges for them and their teams

- **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 (unprompted) that they 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 (unprompted) 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."

Lung CNSs identified a range of difficult challenges for them and their teams

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

"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."

Lung CNSs also identified difficult challenges for patients as a result of COVID-19

- **Changes to diagnostic and treatment pathways and their implications for patient outcomes –** more than half of the responding lung CNSs (27, 54%) raising unprompted 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 unprompted 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."

Lung CNSs also identified difficult challenges for patients as a result of COVID-19

- **Isolation** was another common theme, raised unprompted 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 unprompted 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."

LUNG CANCER NURSING UK

For more information about this survey or the work of Lung Cancer Nursing UK please contact info@lcnuk.org.