

Submission to the All Party Groups for Radiotherapy, Health and Cancer Consultation: Solutions to the COVID induced cancer backlog.

Submission made by Professor David Baldwin (chair), on behalf of the Lung Cancer and Mesothelioma Clinical Expert Group. Correspondence to CEG secretariat, jackie.tebbs@roycastle.org

The Lung Cancer and Mesothelioma Clinical Expert Group (CEG) is the leading independent group of nationally and internationally recognised clinicians, academics, patients, commissioners and representatives from health professional bodies and charities. The CEG provides expert advice on clinical issues in thoracic malignancies, in particular in areas of health policy and strategy. Roy Castle Lung Cancer Foundation acts as secretariat for the Group. More information on the Group is available at <https://roycastle.org/for-healthcare-professionals/clinical-expert-group/>.

The focus for this submission is on Lung Cancer and health services in England but the content applies equally to the other UK countries. Mesothelioma is discussed in section 4.

1. Lung Cancer pre-COVID

Lung cancer is the commonest cause of cancer death for both men and women in the UK. Around 35,000 people die from lung cancer across the UK each year. In 2018, England had around 28,000 deaths, Scotland almost 4,000, Wales nearly 2000 and Northern Ireland 1000.

Outcomes for those diagnosed with lung cancer had, however, been improving in the years up to 2020, with survival estimated to be at around 16% - a doubling from that seen in the late 1990s. Faster diagnosis, the optimisation of the lung cancer pathway, improvements in curative intent treatments, new systemic anti-cancer therapies and the potential for lung cancer screening, all meant that pre-pandemic, there was optimism for the future. Sadly, the pandemic has reversed the progress made and illustrated how important early presentation and diagnosis is, to improving outcomes.

2. Impact of COVID on lung cancer

2.1 Impact of the pandemic on lung cancer referrals and bookings

Two-Week Wait data (Figure 1), shows a massive drop in referrals and booking for lung cancer, due to the pandemic, which have not recovered; in contrast to other cancers.

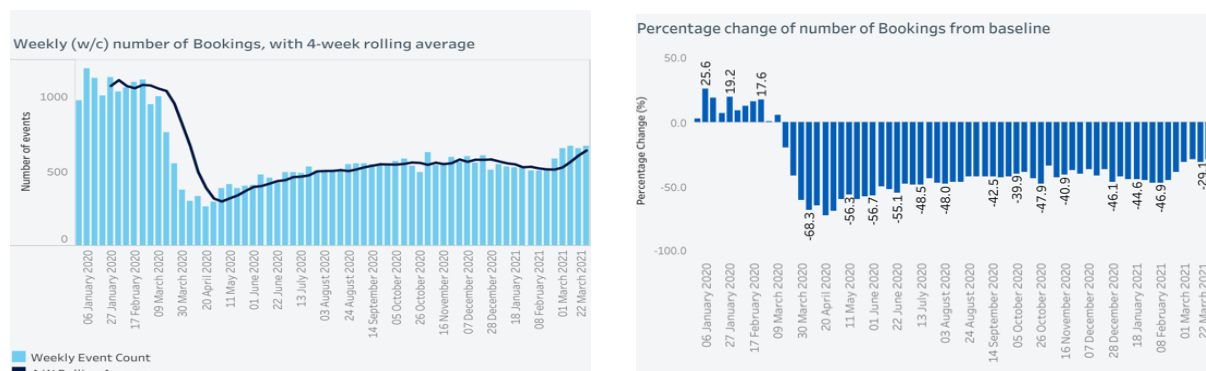


Figure 1 (available from <https://digital.nhs.uk/dashboards/ers-open-data#dashboard>)

Quite clearly, patients have heeded the 'stay at home' message and have been reluctant to seek medical attention or engage with health services in general. In some cases, patients have reported difficulty in accessing general practice and indeed practices were advised to limit access, as part of the necessary measures to control the spread of the virus. For lung cancer, this has been compounded by the similarity in symptoms with COVID.

2.2 Impact on lung cancer diagnoses and surgery

Data from the Rapid Cancer Registration Dataset (Figure 2) shows that lung cancer incidence fell by a third on expected numbers, during the first wave of pandemic. There has been no subsequent compensatory increase. This means that some people with lung cancer will not even have been diagnosed before, sadly, dying of the condition.

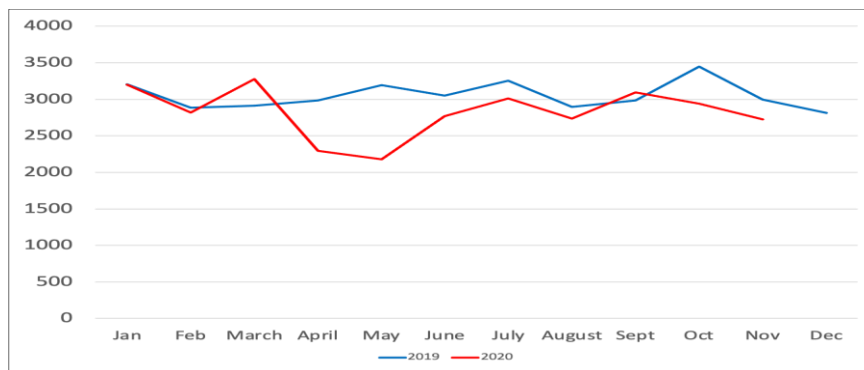


Figure 2 - Lung cancer registrations (from the Rapid Cancer Registration Dataset)

Data presented at the British Thoracic Oncology Group conference, based on the experience at 4 hospital Trusts, after the first wave, already showed an increase in late stage diagnosis (Figure 3).

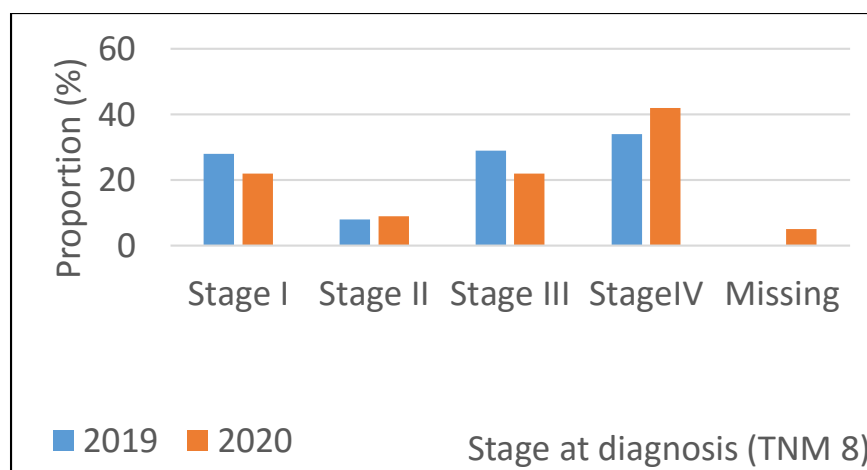


Figure 3. Data from *O'Dowd et al*, poster presentation, BTOG (April 2021). Data from 4 hospital Trusts, limited to April to September 2019 and 2020.

Figure 4 shows data from the Rapid Cancer Registration Dataset for surgery for lung cancer, showing the 30% fall in surgery. Many centres are also seeing more extensive surgery, reflecting the later stage disease

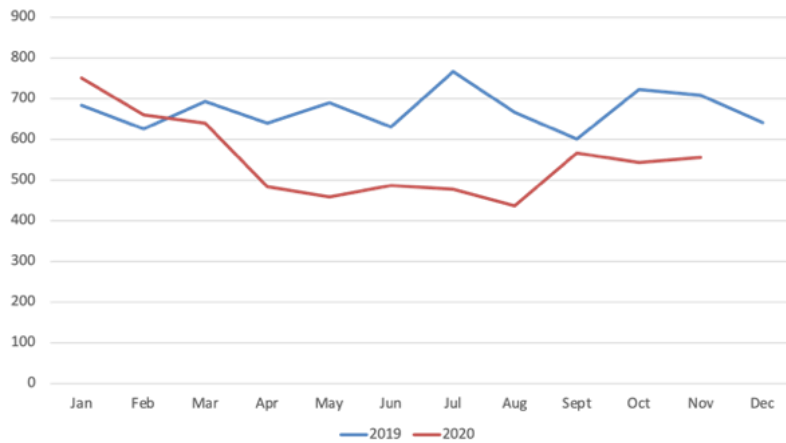


Figure 4. Rapid Cancer Registration Dataset – surgery for lung cancer.

In short, the pandemic has resulted in fewer patients being diagnosed with lung cancer with more at later stage in the disease and fewer potentially curative treatments. This mirrors the experience of those clinicians working in Respiratory Clinics, who describe the experience as “similar to working in lung cancer 20 years ago”.

2.3 The Impact of COVID on the Lung Cancer Pathway

Pre-pandemic, there were many challenges in ensuring optimal care for lung cancer patients – poor compliance in rapid diagnosis, lack of capacity, shortage of workforce. The implementation of the National Optimal Lung Cancer Pathway (NOLCP)

<https://www.roycastle.org/app/uploads/2020/09/National-Optimal-Lung-Cancer-Pathway-3.0.pptx>

is key to ensuring and supporting improvement. The NOLCP, initially developed by the CEG, is a road map for the improvement of lung cancer services, ensuring speedier patient access to diagnostics and treatment. Implementation of the NOLCP is key in ensuring faster diagnosis, optimal service logistics and allowing capacity planning in relation to workforce and physical resources. Importantly it also promotes the highest clinical standards, and reduces waiting times.

COVID has impacted across the entire lung cancer pathway.

- Targeted Lung Health Check Program paused
- General public with potential symptoms of lung cancer, not presenting to General Practice.
- Restricted access to diagnostic services, such as Chest X-Ray, CT scanning, endobronchial ultrasound and PET scanning.
- Alterations to treatment pathways – including reduction in surgery and chemotherapy for lung cancer. With regard to surgery, the need to create COVID secure pathways meant a reduction in thoracic theatre and bed capacity. There is a need to establish whether/if theatre capacity has now fully recovered.
- In palliative and supportive care, social distancing has been especially impactful.

As an immediate response to the pandemic, the CEG advised continued use of the NOLCP as it was readily adaptable to the infection control measures of reducing footfall in the hospital. The CEG also produced the first guidance on the aerosol generating procedure, bronchoscopy and has updated various guidance documents as the pandemic has evolved, as well as advising on other guidance

produced by NICE and the National Cancer Programme Team. The NHS111 algorithm was also modified in December 2020 to include clinical review of persistent cough (more than 4 weeks).

2.4 The Impact of COVID on Lung Cancer Research

During the first wave of the pandemic, all clinical trials in lung cancer were stopped. As we recover from COVID, there is a need to support research and ensure that the current lung cancer portfolio is fully reopened. This challenge will be compounded by the impact from COVID, of a reduction in income to charitable bodies. In turn, this will negatively impact on future research funding.

3. Recovery of lung cancer services post-pandemic

In making recommendations for lung cancer recovery post-COVID, we refer the enquiry to two excellent Reports

- *'COVID-19 Matters. A review of the impact of COVID-19 on the lung cancer pathway and opportunities for innovation emerging from the health system response to the pandemic'* UK Lung Cancer Coalition. (Oct 2020) <https://www.uklcc.org.uk/wp-content/uploads/2020/10/UKLCC-COVID-19-Matters-Report-Oct-2020.pdf>
- *'Learning lessons from across Europe – Prioritising lung cancer after COVID'* . World Economic Forum in partnership with the Lung Ambition Alliance (Jan 2021) <https://www.weforum.org/whitepapers/learning-lessons-from-across-europe-prioritizing-lung-cancer-after-covid-19>

We broadly identify 3 areas where priority is needed –Early detection, Data and Broader recovery and Improvement.

3.1 Early detection

- **Public awareness campaigning.** There is a need for the general public to be aware of symptoms associated with lung cancer and to know that, at this time, health services are open, available and safe to investigate and treat them.
In England, the current phase of the national **'Help Us Help You' campaign**, which launched on 15th February, focuses on lung cancer. The aim of the campaign is to raise awareness of the key symptom of lung cancer – a cough that lasts for three weeks or more. The campaign encourages people who have this symptom and do not have COVID-19 to contact their GP practice, reminding the public that cancer remains an absolute priority and that the NHS is here to see them safely. The campaign can be seen across a full range of communication channels such as TV advertising, video on demand, radio and social media. This campaign is expected to run until the end of May 2021. **With COVID numbers now suppressed and some return to normality, it is important that this campaign be extended and further campaigning, beyond the symptom of cough, be considered.**
Similarly, in Scotland, the *'Detect Cancer Early – Lung Cancer'* campaign and from the charity sector, campaigns such as the Roy Castle Lung Cancer Foundation, *'Still Here'* campaign, have encouraged symptom awareness and availability of health services during this time.
- **Incidental Findings of Pulmonary Nodules.** A significant proportion of early stage lung cancer is detected from within-hospital referrals for scans performed for reasons unrelated to lung cancer (incidental detection). This contribution to early detection was substantially reduced during and post-pandemic due to reductions in overall scanning of some cardiothoracic conditions. This is due in part to the stay at home message, but also due to

overall lower hospital activity for non-urgent conditions; this has yet to fully recover in all areas.

- **Role of Primary Care.** It is important that once patients come forward, there is speedy access to diagnostic services. As previously indicated, the overlap of symptoms of lung cancer and COVID means that lung cancer may not be suspected. During the pandemic, NHS111 clarified the advice and referral process for patient callers, ensuring that patients with a persistent cough are directed to a healthcare professional, usually a GP, irrespective of COVID status. **It is vital that this advice from NHS111 is continued to be offered post pandemic.**

Messaging for Primary Care – The CEG has developed a Document

<https://www.roycastle.org/app/uploads/2020/09/Differentiation-of-the-Cs-in-lung-cancer-Cancer-vs.-COVID.pdf> and Infographic (Figure 4) for healthcare professionals, **'How to differentiate lung cancer from COVID 19'**. Wider circulation, across primary care, would be beneficial in raising awareness.

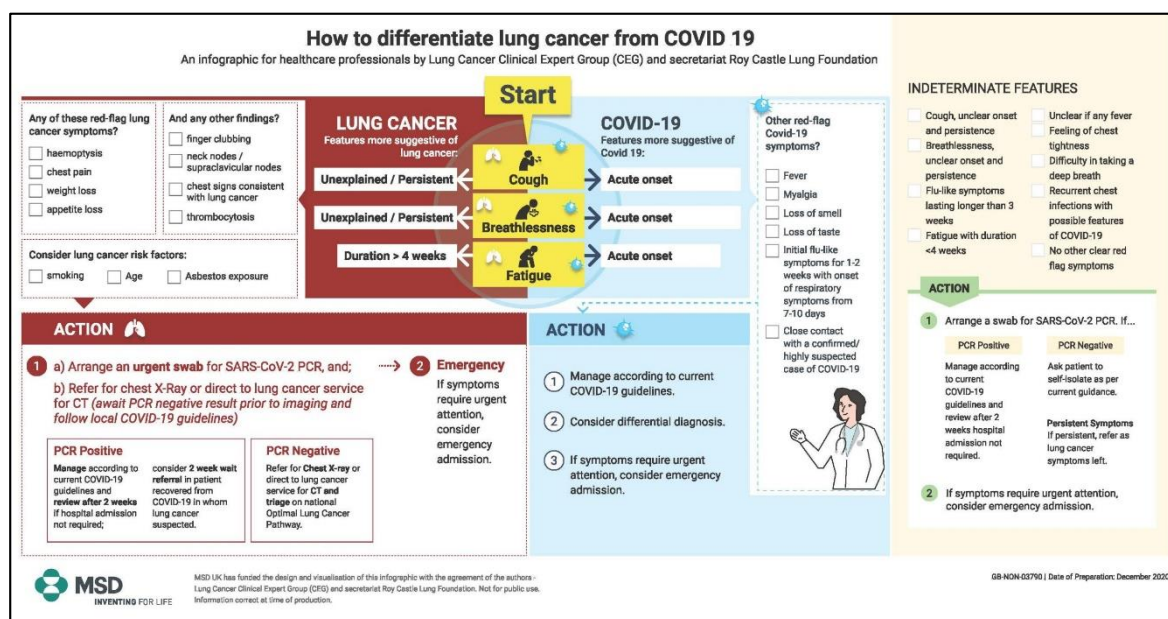


Figure 4

- **The Targeted Lung Health Check programme (TLHC)** is working with 23 CCGs in England, with high lung cancer mortality rates and invites high risk individuals to a lung health check with low dose CT. The programme was just getting underway in early 2020, when the pandemic resulted in a pause in this and the other cancer screening programmes. The programme has now partially resumed, with an addendum to the protocol, to ensure COVID safety. There is commitment to a further roll out of the programme. **Speedy implementation of the TLHC programme is of vital importance in improving outcomes for lung cancer and in contributing to the reversal of the impact of COVID.**

3.2 Data

The COVID pandemic has highlighted the need for **high quality data in real time**. We are fortunate in the lung cancer area to have the National Lung Cancer Audit (NLCA) - a national and internationally recognised audit, led by clinicians. Beyond the traditional scope of the NLCA, there is a need to understand the implication of changes made due to COVID on diagnostics, treatments and services, including the switch from face-to-face consultation to virtual patient consultation. Where these are evaluated and found to be beneficial, changes to ongoing practice should be adopted. There is also a need to assess the impact of the TLHC programme across the lung cancer pathway. Furthermore, data needs to be in real time, feeding back to clinicians and local service managers. **The NLCA, as it aims to track recovery from COVID, in as near to real time as is possible, needs to be adequately resourced and supported to do so.**

3.3 Broader recovery and improvement:

- Already, there is evidence for ‘missing’ lung cancer patients and a shift towards late stage diagnosis, resulting from the pandemic. As services are restored, it is essential that patients present early to primary care and primary care responds by referring early. This means that more patients will be eligible for curative treatments and also those with advanced disease will be in a better physical condition to allow them the benefit from modern systemic anti-cancer treatment. Lung cancer is a rapidly fatal cancer for many and time is critical. It is important that services have the capacity to deal with additional referrals and to implement **the National Optimal Lung Cancer Pathway** which ensures rapid diagnosis and treatment.
- Of importance to this is diagnostic capacity and as such, ensuring that funding is available for the recommendations made in Professor Sir Mike Richards review, *‘Diagnostics: Recovery and Renewal’* (NHSE).
- Furthermore, **workforce** issues need to be addressed. In particular, for lung cancer, planning for shortages in Thoracic Radiologists, Specialist Clinical Oncologists and Lung Cancer Clinical Nurse Specialists (CNSs).

With regard to Lung Cancer CNSs, there is not only a need to address shortages but, with more late-stage patients and more complex treatments, a need to increase number of posts. CNSs are vital in improving patient quality of life and in addressing psychological care – of particular importance since COVID. They have a key part in the NOLCP, not only in ensuring good communication between primary and secondary care but also in reducing the need for GP appointments and hospital admissions.

Prehabilitation aims to maximise patient fitness, nutrition and wellbeing, before treatment, in order to improve outcomes. CNSs and also Allied Health Professionals, such as dedicated dieticians and physiotherapists, are not only key to ensuring better prehabilitation but also, in ensuring post treatment rehabilitation and symptom management. With COVID causing patients both to present later and with greater psychological distress, there is a need for these AHPs to be part of workforce planning in lung cancer.

- **Changes to practice and new ways of working prompted by COVID** need to be evaluated and adopted, if found to be beneficial. These will include –
 - o Direct access to CT scanning, from General Practice, for high risk lung cancer patients.
 - o Changes to treatment pathways – less chemotherapy, more immunotherapy and target therapies being used earlier in the treatment pathway.Virtual consultations (telephone, video or online), replacing some traditional face to face consultations. For lung cancer, it is likely that the future will be a mix of the two, with a focus back to face to face. However, patient preference and clinical necessity need to be assessed, to ascertain in what circumstance.

- **Patient Information**, in particular, the availability of written information, has been curtailed during the pandemic. Reopening of Cancer Information Centres and availability of high quality patient focused lung cancer Information is a priority.

4. Mesothelioma

Across the UK, around 2,700 patients are diagnosed each year, with mesothelioma and it accounts for around 2,400 deaths. As with lung cancer, COVID has had a massive impact. The charity, Mesothelioma UK, reports the following -

- During the pandemic, patients with mesothelioma and those worried with symptoms failed or chose not to seek medical help:
 - Access to GP assessment was difficult, with many patients reporting long telephone queues and lack of access to face-to-face consultations
 - Committed to shielding advice and having fear of mixing with others, stayed at home.
 - With no hospital visits allowed, did not wish to be separated from family. With hospital visiting remaining an issues, this is still a problem, as patients tend to be elderly, frail and have a poor prognosis.
- Alterations to treatment. During the pandemic, systemic treatments (chemotherapy and immunotherapy) for mesothelioma patients virtually stopped. However, for those patients able to fund their treatment privately (mainly through their civil claims), there was no delay or interruption to chemotherapy or immunotherapy treatment. The majority of this was delivered through Home Care private providers (Health Care at Home), with clinicians using virtual platforms for consultations. Patients felt safe in their own homes. **There is a need to investigate the establishment of NHS home care services in oncology, especially for our more vulnerable cancer patients.**
- Data. The National Mesothelioma Audit (originally part of the NLCA) has been funded by Mesothelioma UK since 2014. Currently, invitations are being sought for tender for the next 3 years. Like the NLCA, it is a world leading audit and a focus for future audit will be to interrogate data from the pandemic and monitor recovery.
- Workforce. There are currently 34 **Mesothelioma Clinical Nurse Specialists** across the UK, most being charity funded. As above, the role of the CNS is vital and even more so at this time. To ensure adequate cover across the UK, an additional 10 posts are required.
- Support for Carers. Through survey work, it is clear that in switching to virtual consultations and limited visiting, support for carers has suffered during the pandemic. There have been few or no opportunities for carers to ask questions, especially important for those caring for folks near end of life. It is important as services recover, that carers are not forgotten.

5. Summary

In summary, lung cancer and mesothelioma patients and services have been hugely negatively impacted by the COVID pandemic. As we return to normality, there needs to be a focus on early detection in lung cancer, by both extending the '*Help Us Help You – Lung Cancer*' public awareness campaign, improving access to clinical evaluation and prompt referral and ensuring implementation of the Targeted Lung Health Check Programme, as soon as is possible. Implementation of the National Optimal Lung Cancer Pathway remains a major priority to ensure rapid diagnosis and treatment through optimal logistics, capacity planning and application of the highest clinical standards.