Written evidence submitted by the Less Survivable Cancers Taskforce (DEL0286)

About the Less Survivable Cancers Taskforce: The six less survivable common cancers (lung, pancreatic, liver, brain, oesophageal and stomach) are responsible for half of all deaths and make up a quarter of cancer cases each year in the UK.

The five-year survival rate for the 80,000 people diagnosed with these cancers each year is only 14%. These cancers have not seen the same improvements in survival rates that other cancers have in the last forty years. The Less Survivable Cancers Taskforce (LSCT) brings together six charities representing patients from each of these cancers:

- Action Against Heartburn
- The Brain Tumour Charity
- The British Liver Trust
- Guts UK
- Pancreatic Cancer UK
- Roy Castle Lung Cancer Foundation

Summary and recommendations

- People with one of the less survivable cancers are typically diagnosed late and have a poor prognosis. Where treatment is possible, either curative or life prolonging, this must be given as soon as clinically possible. It is therefore vital that people with symptoms, including vague symptoms, are encouraged to come forward to their GPs, and that there are fast diagnostic pathways and direct pathways into the new Covid-free cancer hubs for treatment.

- We are extremely concerned about the reduction in urgent referrals for cancer diagnosis. Significant energy and resource is needed to ensure that people who have symptoms are encouraged to come forward, and are able to access timely diagnostic tests in a Covid-free environment.

- We support NHS England's ambition to diagnose 75% of cancers at an early stage by 2029. This was always going to be a huge challenge for the less survivable cancers (currently only a quarter are diagnosed at stages 1 or 2) but given the current additional challenges in diagnosing people who have one of the less survivable cancers, additional resource will be required to focus on diagnosing these cancers earlier and faster if NHS England is to meet this ambition.

- We are pleased that NHS services are now stepping up non-Covid-19 urgent services, including cancer diagnostic and treatment services in Covid-protected cancer hubs and environments. However, we are concerned to still hear of treatments being delayed or cancelled due to increased risks or the reduced capacity of the health service.

- People with less survivable cancers must not be de-prioritised or neglected because they are hard to treat.

Recommendations:

1. Significant energy and resource must be deployed into encouraging people with symptoms to come forward for testing in Covid-free environments. This must include vague symptoms such as changes to bowel habits, sudden weight loss, abdominal pain, headaches, bleeding and persistent coughs.

2. Progress made with the Rapid Diagnostic Centres must be continued and accelerated, working in partnership with the cancer hubs to diagnose people quickly and enable prompt access to treatment.
3. To enable earlier diagnosis of the less survivable cancers, progress needs to be made in developing diagnostic tests such as Cytosponge, breath and saliva tests. Laboratory capacity for these projects be adversely affected by the crisis.
4. Cancer hubs must be able to treat people with the less survivable cancers (lung, liver, stomach, pancreatic, brain and oesophageal) with urgency, so we don't see a further drop in outcomes for these cancers. People with these cancers must not be deprioritised or neglected.
5. Covid-free cancer services must be prepared for an increase in demand for services as they work through backlogs and respond to people who may have inadvertently delayed diagnosis. Cancer services must also be developed with the capacity to cope if there is a second peak of the virus.

Full submission

1. The LSCT welcomes this inquiry to ensure that core NHS services are maintained during the pandemic and beyond. Since the outbreak of the pandemic, our six charities have been focused on providing patients with COVID-19 related information and support and are working closely with relevant colleagues in the NHS to provide this. We fully support NHS England, Public Health England and all frontline healthcare professionals in their work to combat COVID-19, protect those most vulnerable, and reconfigure other critical healthcare services.

2. **Maintaining a focus on early diagnosis for all cancers, in particular the less survivable cancers, is vital.** The less survivable cancers are often hard to diagnose with patients presenting with vague and non-specific symptoms. Early and fast diagnosis is crucial for these cancers to allow treatment and increase survival rates. Before the crisis, late presentation of these cancers was a huge issue, for example over a third of liver cancer patients were diagnosed at A&E. Now cancer referrals from primary care have dropped by 63% meaning that we are likely to see an increased number of patients coming through diagnosis at a more symptomatic/advanced stage.

3. Significant energy and resource is needed to ensure that people who have symptoms are encouraged to come forward, and are able to access timely diagnostic tests. Some of our member charities have continued to receive calls from people with 'red flag' symptoms who say they fear adding to the burden the health service is under the health service or NHS 111. The work that has begun on Rapid Diagnostic Centres (RDC) in Cancer Alliances should be seen as a complement to the cancer hubs and RDC models of care should be accelerated, wherever possible.

4. We are aware that treatment hubs for cancer, such as The Christie in Manchester, have been kept 'COVID free' to protect and reassure patients. Patients with potentially cancer-related symptoms must be referred to centres which are similarly kept free of infection to encourage people to come forward when they experience cancer symptoms. Similarly, endoscopy services must be restarted in a Covid-free environment.

5. Technological advances often need to be accelerated in times of crisis, and this could be an opportunity to accelerate research and development of urgently-needed diagnostic tests such as Cytosponge (a 'pill on a string' to gather samples testing for Barrett's oesophagus, a precursor to oesophageal cancer and other relevant conditions), breath and saliva tests.

6. **People with a less survivable cancer must have urgent access to treatment at the cancer hubs.**

7. Cancer hubs are an essential solution to the challenges presented by the Covid-19 pandemic and it is vital that anyone diagnosed with a less survivable cancer is able to access treatment as a matter of urgency at a cancer hub. Delays will result in poorer clinical outcomes in most cases. For example, only 10% of people with pancreatic cancer are able to have surgery due to the late stage this cancer is generally diagnosed at. This shows the need for fast access to surgery before the cancer becomes inoperable.

8. NHSE prioritisation criteria for systemic anti-cancer therapy (SACT) is based on the survival gain for treatment. The survival gains for chemotherapy for the less survivable cancers are in the order of months and not years, therefore, it is likely any treatment and blanket resource prioritisation and rationalisation will impact people with a less survivable cancer disproportionally.

9. Surgery for these six cancers is invasive and complex and patients will often need to have access to intensive care beds in a COVID-free environment for recovery. A lack of ventilators and HDU/ICU beds (a knock-on effect from COVID-19) could result in a potential reduction in surgical capacity and needs to be addressed.

10. The reduction in presentations of people with cancer at the moment means that there may be a surge in new diagnoses in coming weeks or months. Cancer hubs, and diagnostic capacity, must be prepared for this potential increase in demand.

11. At all times, and especially now, discussions with patients are essential - they need to be informed as to their options and choices, although with the associated risks and benefits, and agree with the treatment decision. Any deviation from the normal standard of care and the implications of this deviation must also be discussed and agreed with the patient.

May 2020