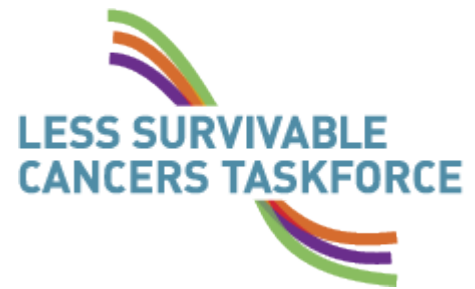


Less Survivable Cancers Taskforce Cancer Plan Submission



Introduction

The Less Survivable Cancers Taskforce is a coalition of six charities all representing a cancer that has a survival rate of under 30% over five years.

These charities are:

Action Against Heartburn

British Liver Trust

Guts UK

Pancreatic Cancer UK

Roy Castle Lung Cancer Foundation

The Brain Tumour Charity

We have produced this document in response to NHS England's call for evidence regarding our experiences and priorities for cancer care.

This paper will take you through the four top priorities for the taskforce, detailing why they are important and giving examples of good practice in the disease areas with clear recommendations.

Executive Summary

This paper will prioritise four key areas:

- Screening and diagnosis
- Pathways to treatment
- Access to the best treatment
- Research

We believe that focusing on these four areas is integral to ensuring better survival rates for the less survivable cancers, as well as guaranteeing that all patients get access to the best treatment and care.

Patients with one of the six less survivable cancers are five times less likely to survive for five years or more in comparison with patients who have one of 14 other common cancers.

Screening and diagnosis

Despite accounting for half of common cancer deaths the less survivable cancers still suffer from low awareness amongst the public and health practitioners. Delays in diagnosis have a detrimental effect on survival of these rapidly-advancing diseases, which are currently difficult or impossible to treat at later stages.

However, there are promising developments that, if accelerated, could potentially help to achieve earlier diagnosis.

Survival for oesophageal cancer are dramatically better when a diagnosis is made at an earlier stage. The key to achieving this is to diagnose those with Barrett's Oesophagus. The annual cancer risk from Barrett's Oesophagus is small, but accelerates when dysplasia is present.

More important than the annual risk, per patient year, however, is the *lifetime* risk. A patient aged 30 years with newly developed Barrett's Oesophagus may have a 12-25% risk of developing adenocarcinoma by the age

of 80 years.¹ This precursor condition situation is relatively unusual amongst cancer types, and it is essential that the opportunities are taken to monitor and treat patients who may be at risk some years ahead. Monitoring and surveillance of Barrett's Oesophagus patients is sometimes inconsistent, and tends to work best in dedicated clinic lists with more time available per patient.

Advances in treatment pathways are always profoundly welcome, but the patients need to enter their GP surgery in the first place. The oesophago-gastric *Be Clear on Cancer* was effective in raising awareness of the public health risk of persistent heartburn, but this needs to be repeated in a long term strategy. More should be done to include clear and graphic warnings on packets of over-the-counter heartburn medication, since we know that many people diagnosed with oesophageal adenocarcinoma have been self-medicating on heartburn remedies for years beforehand. The campaign revealed that only 1 in 2 people (55%) would go their doctor, even if they had had heartburn most days for over 3 weeks.²

To date there is not screening test for pancreatic cancer. Public awareness of the symptoms of pancreatic cancer also remains dismally low. A ComRes survey carried out by Pancreatic Cancer UK in 2016 found that 74% of the public could not promptly name a single symptom of the disease.

The symptoms of pancreatic cancer can also be common and vague. This is why we are keen to see the roll out of public awareness campaigns such as *Be Clear on Cancer's* vague abdominal symptoms campaign which ran as a pilot in the Midlands in 2017 and had promising results. It covered issues such as bloating, diarrhoea and discomfort. Such programmes can highlight symptoms for many of our cancers, including oesophageal and stomach, in the absence of screening. It had promising results with more people seeing their GP.

For all of our cancers, where awareness of symptoms improve, we are more likely to see an increase in referrals from GPs to multidisciplinary diagnostic centres (MDCs) for vague symptoms. This is something that we would like to see rolled out across the country.

An example of a greater public and GP awareness of signs and symptoms campaign for one of the less survivable cancers is *HeadSmart*. *HeadSmart* is a multi-award-winning, UK-wide campaign based on research funded by The Brain Tumour Charity at The University of Nottingham (2003-2006). The research investigated the reasons behind delayed diagnosis and identified common signs and symptoms by age groups. It aims to educate the public and healthcare professionals about the signs and symptoms of brain tumours in children and young people, to reduce diagnosis times. This will save lives and reduce long-term disabilities. Our goal is to reduce average diagnosis times to 4 weeks or less in line with NHS targets.

The campaign is a partnership between The Brain Tumour Charity, The Children's Brain Tumour Research Centre at The University of Nottingham and the Royal College of Paediatrics and Child Health (RCPCH). It is endorsed by the RCPCH and the guideline for healthcare professionals has received NHS Evidence accreditation. To date it has helped to halve average diagnosis times for childhood brain tumours from 13 weeks to 6.5.³

In regards to lung cancer the University Hospital of South Manchester Trust (UHSM) offered people aged between 55 – 74 a 'Lung Health MOT' which consisted of a free health check and an on the spot scan. They found that the number of patients discovered at stage four, which is usually incurable, reduced from nearly 50% to just over 10%. Over 2,500 people were checked, with about half then being offered an immediate CT scan. Those scans led to 42 cancers being discovered, with nearly 90% of those diagnosed were offered curative treatment. A further 20% of those who attended were diagnosed with chronic obstructive pulmonary disease.⁴

On 21st November 2017, Simon Stevens, chief executive of NHS England, announced plans to roll out a Lung Health Check programme across England. However, to date, there is no implementation plan for this in place.

There is additionally an emerging capacity issue around diagnostics and lung cancer. This is partly around radiologist and reporting (with increased demand in areas where there are pilot developments, but also in areas where referral rates are increasing on the back of improved awareness or action by Primary care). In

¹ UK Barrett's Oesophagus Registry

² <https://www.gov.uk/government/news/be-clear-on-cancer-campaign-highlights-links-between-heartburn-and-cancer>

³ <https://www.headsmart.org.uk/clinical/clinical-guideline/>

⁴ <https://www.roycastle.org/news/lung-health-mot-scheme-could-save-thousands-of-lives-nationwide>

2009 there was a study by Doncaster PCT that coupled public awareness with GP training and vigilance which led to a 22% increase in referrals from the GP surgeries⁵.

Recommendation

NHS England to support public awareness campaigns and diagnostic programmes such as ACE MDCs for the less survivable cancers. Ensuring that the Cancer Workforce Plan creates extra capacity for diagnosing our cancers earlier.

Pathways to treatment

Late diagnosis and slow progress to treatment can severely limit treatment options for patients, who then face poorer survival prospects at 12, 24, and 36 months onwards.

Streamlined one-stop shop clinics are vital for speeding up care pathways for hard to diagnose and hard to treat cancers. One-stop clinics minimise the number of appointments required during diagnosis and treatment decision, reducing time from referral to treatment by 13 days.

Surgery to remove pancreatic cancer offers patients the only realistic opportunity for potential cure and long-term survival. University Hospitals Birmingham (UHB) NHS Trust has developed a pathway to provide early surgery where the time to surgery was reduced from 65 to 16 days. Significantly more patients underwent potentially curative surgery in the fast-track group (97% vs 75%). And critically by getting into treatment earlier, people can avoid having to have two major surgeries, as pancreatic cancer patients often suffer from jaundice as the pancreas malfunctions and they need to have a stent surgically inserted. Recovering from this surgery is hard and it also delays being able to have potentially curative surgery. By implementing fast track surgery it's possible to have one surgery rather than two, saving the NHS money and patients' having to undergo two major surgeries. This type of surgery is recommended in the recent NICE Guidelines for pancreatic cancer but has not been rolled out universally. The study has shown savings of over £3000 per patient.

Dr Faluyi and Dr Palmer in Clatterbridge Cancer Centre (CCC) have shown that pancreatic cancer who receive care from dedicated clinics for advanced stage inoperable patients can improve late stage pancreatic cancer outcomes. Patients seen in these clinics initiated treatment within 18 days on average after initial review as opposed to 28 days when patients were seen in non-specialist oncology clinics. The centralised dedicated clinics achieved 24% more patients having chemotherapy, with a median survival of five months as opposed to three months.

According to a paper in the British Medical Journal, in brain cancer there was a lack of interest in neurosurgical oncology subspecialisation, and less than ideal patient pathways as a result. One problem identified was the low rate of tumour resection.⁶

A pathway of care was established, commonly known as the Cambridge Model, in which all patients were discussed pre-operatively in a Multi-Disciplinary Team (MDT) meeting and then directed into a new surgical neuro-oncology clinic providing first point of contact.⁷

The outcomes of this have included an increase in patients discussed pre-operatively in an MDT (66% rising to 87%; $P=0.027$), an increase in the rate of surgical resection (from 40% to 80%) and more patients being admitted electively (from 25% to 80%; $P<0.001$). There was a reduction in the median length of stay (8 days reduced to 4.5 days; $P<0.001$). For the cohort of GBM patients that went on to have chemoradiotherapy it improved median survival to 18 months, with 35% of patients alive at two years, comparable to international outcomes.

Professor Keyoumars Ashkan, Consultant Neurosurgeon and Honorary Reader with specialist interest in functional neurosurgery at Kings College Hospital, has suggested that sub-specialisation itself has been a critical factor in driving the technological innovations in neuro-oncology and remains the momentum pushing forward the future research. Professor Ashkan also advocates that patients deserve a specialist team capable of providing them with full undivided care and attention at every step of their care.

⁵ <http://www.thensmc.com/resources/showcase/early-detection-lung-cancer>

⁶ Price, Stephen J., Development of an Integrated Subspecialist Multidisciplinary Neuro-oncology Service. BMJ.

⁷ Price, Stephen J., Development of an Integrated Subspecialist Multidisciplinary Neuro-oncology Service. BMJ.

The National Lung Cancer Optimal Pathway which has now been adopted by NHS England, has been welcomed by those working in the field. It is crucial that Cancer Alliances prioritise the Lung Cancer Pathway implementation. This pathway would see the length of the pathway to the start of treatment be reduced to 49 days compared to the current standard of 62 days. The pathway include CXR to CT in less than 24 hours, rapid turnaround time for testing and daily respiratory clinics.

Another factor influencing delays to treatment in lung cancer is the need for pathological investigation for those with advanced lung cancer where potential mutations (EGFR and ALK) may affect the treatment pathway, or where immunotherapy may be a treatment option depending in some instances on confirmation of PDL1 status. Equitable and speedy access to new molecular diagnostics (EGFR< ALK< ROS-1, PDL-1) should be seen as a priority to help improve outcomes.

Recommendation

NHS England should develop or implement optimal care pathways for less survivable cancers similar to the pilots for prostate, lung and bowel cancers. Funding can be secured from the National Cancer Transformation Programme.

Access to the best treatment

It is essential that patients have access to the best treatment and that these are available throughout the country. Where patients are being treated should not determine the quality and availability of treatment available to them. It is also essential that new treatments are made available as quickly as possible to ensure that patients get the best outcomes possible.

The relatively new treatment of radiofrequency ablation (RFA) enables patients with dysplastic Barrett's Oesophagus to have the suspect cells removed, and often the risk of future cancer removed. RFA is not available consistently across the country and should be made available to cancer treatment centres.

Over 96% of respondents, within the brain tumour community, believe they should have the right to try an experimental treatment, even if may not have a better outcome than a standard treatment.

All cancer patients need to have access to a holistic needs assessment from the point of diagnosis to ensure that they are able to tolerate treatment and so that there is a joining up to the care that they need and a whole person approach. For patients with LSCs they need this straight away due to the often rapid progression of these diseases. A key issue for a range of our cancers including oesophageal and pancreatic is the need for specialist and timely dietary support. Without this support people can suffer from cachexia and become malnourished quickly which hugely affects their ability to take part in daily activities, affects their ability to stay well whilst they are waiting for treatment and to tolerate treatment; which will ultimately enable them to survive longer.

In regards to the Accelerated Access Pathway one pressing issue is that the accelerated process will only apply to the NHS and not the regulatory parameters surrounding new drug treatments. With conditions where survival is low the regulatory process must support new medicines coming to market as quickly as possible.

There will still be in place a lengthy process of securing regulatory approval from either the European Medicines Agency or the UK Medicines and Healthcare products Regulatory Agency, both of which require the completion of a clinical trial process for safety and efficacy purposes.

Technology Appraisals need to value relative survival gains for LSCs as well as absolute, and appreciate the challenges of running trials for diseases with high short-term mortality rates. Only then will life-extending treatments be made available to more patients in need.⁸

We are concerned that recent decisions made by NICE and NHSE may undermine patients' access to breakthrough immunotherapy medicines that may be costly to the NHS. It's essential that there is a funding settlement that means that we can continue to offer world class cancer care in England and also to address the poor survival gains across our cancers with these new research breakthroughs.

⁸ <http://lessurvivablecancers.org.uk/help-us-close-the-gap/a-research-funder/>

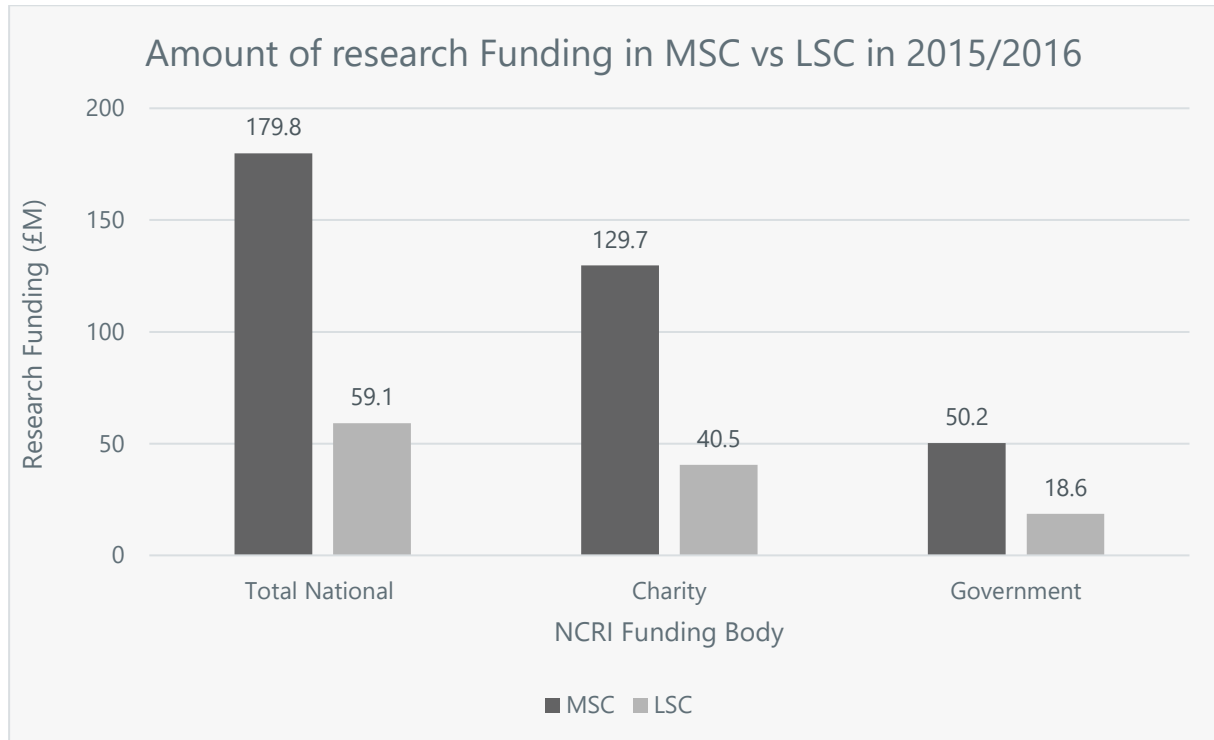
Recommendation

NHS England to look at expanding the Accelerated Access Pathway to include more drugs applicable to less survivable cancers.

Research

In the decade 2007-2016 LSC received 6.5% of total NCRI budget. Also we have a breakdown for government vs charity data which shows that charities have invested more into research than government.

In 2015/16 more survivable cancers received three times more funding than less survivable cancers, with the charity sector investing two times more funding than the government in less survivable.



According to a report by nfpSynergy, 81% of the public believe everyone diagnosed with cancer should be offered the opportunity to take part in a clinical trial.⁹

According to the National Cancer Research Institute those diagnosed with a less survivable cancer are far less likely to participate in a clinical trial. Full data is not available for each individual cancer type, due to the way the cancers are grouped but it shows that in 2016–17, brain patients sat at 2.27%, lung 5.54% and upper gastrointestinal 6.03%. Comparatively breast had 10.64%, bladder 9.05% and prostate 8.06%.¹⁰

Recommendation

NHS England to look at ways to invest in more research and incentivise clinical trials for the less survivable cancers and to approve a themed research calls on LSCs for NIHR funding.

Survival target

The Less Survivable Cancers Taskforce recommends that NHS England creates a 5 year survival target for the less survival cancers to help address variation and inequality in diagnostic services, treatment and care. The Taskforce believes the ambition should be to double 5 year survival for each of the less survivable cancers in the next ten years. This would take the combined 5 year survival from 14% to 28% by 2029.

Currently NHS England's first edition Cancer Dashboard currently only offers data for four cancers, and its overall cancer survival ambition is not broken down on a per-cancer basis. Making data available will be critical if we are to track success in improving outcomes for the less survivable cancers.

⁹ Charity Awareness Monitor, July 14, nfpSynergy.

¹⁰ <http://csg.ncri.org.uk/about-the-csgs/clinical-studies-groups>

In 2016, NHS England made £200m available to ensure that the Independent Cancer Taskforce's ambition of 57% of cancers being survivable by ten years or more by 2020, and 75% surviving one year or more.¹¹

This level of aggregated data will not guarantee improvements in the less survivable cancers, and track and monitor the progress that is made. We know that what is measured gets done, and without a clear target to incentivise the implementation above, it is difficult to see that meaningful progress will be achieved in the future.

¹¹ <https://www.england.nhs.uk/cancer/early-diagnosis/>