Response to Health & Sport Committee inquiry on the Preventative Agenda

About Us

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours, making a difference every day to the lives of people with a brain tumour and their families.

We fund pioneering research to increase survival and improve treatment options. We raise awareness of the symptoms and effects of brain tumours to drive earlier diagnosis and to help families cope with everything that the diagnosis of a brain tumour brings. We provide support for everyone affected so that they can live as full a life as possible, with the best quality of life.

We are committed to having the biggest possible impact for every person affected by a brain tumour, to defending the most amazing part of the human body, so that getting the diagnosis of a brain tumour no longer means a death sentence.

Preventative Agenda Inquiry Questions

1. **Which areas of preventative spending/the preventative agenda would it be most useful for the Health and Sport Committee to investigate?**

We believe that a focus on preventative spending to drive early and accurate diagnosis of cancer and increase awareness of the signs and symptoms of cancer would be useful for the Committee to investigate.

As a Charity, one of our biggest priorities is to work to reduce diagnosis times and improve accuracy of diagnosis so that brain tumours are treated earlier, with the best possible treatment at the right time.

Last year, the Scottish Cancer Patient Experience Survey highlighted whilst the majority of cancer patients (75%) were referred onto hospital for their cancer by their GP, 37% of people with a brain tumour went directly to hospital, the highest figure for any cancer type. This figure highlights the lack of awareness of brain tumour symptoms, and the challenge of late diagnosis compared to other cancer types. (1)

One of our key initiatives to drive earlier diagnosis is our HeadSmart early diagnosis campaign for childhood brain tumours. The HeadSmart campaign is based on research funded by the Brain Tumour Charity at the University of Nottingham (2003-2006), which investigated the reasons behind delayed diagnosis and identified common signs and symptoms by age groups.

We raise awareness of these signs and symptoms through distributing symptoms cards to healthcare professionals, schools and the general public. Our goal is to reduce diagnosis times to 4 weeks or less in line with NHS targets. Since the launch of the campaign in 2011, average diagnosis times have fallen from 9.1 weeks to 6.5 weeks.

Whilst we have worked with the Teenage Cancer Trust to ensure that HeadSmart materials are distributed to every school in Scotland, increasing national awareness of the signs and symptoms of brain tumours identified in the HeadSmart campaign is crucial to reducing diagnosis times further in Scotland and the rest of the UK.

We recognise the Scottish Government’s efforts to increase awareness of common cancer signs and symptoms through the Detect Cancer Early programme, and welcome the pledge in the *Beating Cancer: Ambition and Action Plan* to support the development of Teenage Cancer Trust’s schools-based education programme through this work.
However, we believe that there is a need for future campaigns to focus on cancers with low survival, which often have vague symptoms like brain tumours. We call on the Scottish Government to evaluate the current Be Clear on Cancer campaign from Public Health England, which focuses on vague abdominal symptoms, to draw any lessons which can be used for future campaigns by Detect Cancer Early.

Given the success of HeadSmart campaign for children, teenagers and young people, we are now in a position to use this as a template to drive forward a similar campaign targeting earlier diagnosis of brain tumours in adults.

We have recently commissioned research into the diagnostic pathway for brain tumours in adults at the University of Edinburgh. This project is being led by Dr Paul Brennan, and is aimed at understanding the reasons why some adult patients take longer than others to be diagnosed with a brain tumour.

The aim of our research is to produce simple guidelines to help general practitioners to better identify which patients may have a brain tumour. These patients can then be rapidly referred to a specialist for further investigations such as a brain scan.

Further progress in preventing long-term side effects of brain tumours can be made by improving the accuracy of diagnosis through prompting biomarkers and molecular testing as part of diagnosis.

Biomarker testing involves taking a small amount of tumour and analysing the biology of it. Whilst only suitable for some brain tumour types, these tests may be helpful in diagnosing a tumour, predicting the speed a tumour will grow, predicting how well it may respond to certain treatments or eligibility for a particular clinical trial and planning appropriate and individual treatment.

Currently, there are Quality Performance Indicators around molecular analysis of two biomarkers in Scotland: 1p19q, which can be useful in diagnosing and predicting long-term survival in some types of brain tumour, and the MGMT test, which can be useful in predicting how effective chemotherapy treatment is likely to be for low-grade patients.

However, the Scottish Adult Neuro Oncology Network (SANON) recently found that in 2015, all Neuro-Oncology Networks in Scotland failed to meet QPI targets around molecular analysis. (2) For instance, just over a third of patients with glioblastoma (high-grade brain tumour) had their tumour tested for MGMT promoter methylation status within 21 days of surgery in Aberdeen or Dundee.

Greater focus and resources for molecular testing and analysis would help to improve the accuracy of diagnosis for brain tumour patients across Scotland, helping to prevent spending on costly treatment options which are unsuitable for the particular type of brain tumour that they have.

2. How can health boards and integrative authorities overcome the (financial and political) pressures that lead to achieve spending/a focus on fulfilling only statutory duties and targets, to initiate and maintain preventative spend?

At a time of financial constraint for the NHS, it is important that Health Boards and other agencies work with health and social care charities to enable them to promote cancer awareness and education programmes across Scotland. These charity interventions are usually delivered free of charge, whether the HeadSmart campaign materials or Teenage Cancer Trust’s school presentations.

It is critical that Health Boards and statutory agencies do not duplicate this information provision from charities and work collaboratively to disseminate and deliver these evidence-based resources to healthcare professionals, patients, schools and the general public.

Secondly, Health Boards and other agencies can draw on research which shows that investment in cancer awareness programmes can lead to the NHS diagnosing patients earlier, which in turn can save lives and reduce treatment costs. In 2014, Incisive Health and Cancer Research UK highlighted the cost savings that could be delivered if NHS agencies were able to achieve the level of early diagnosis of the best countries in Europe across a range of cancer types. (3)

These averted costs should instead be used to fund early diagnosis programmes and better treatments for those who need them. This shows that health services should be able to plan early diagnosis programmes in the expectation that they can achieve significant health gains for cancer patients.
Recent research by the University of Stirling confirmed that after one of the Teenage Cancer Trust’s presentations, students’ recognition and recall of cancer warning signs and risk factors significantly increased, compared to a fourth school which did not receive the intervention. (4)

3. **How could spend that is deemed to be preventative be identified and tracked more effectively? What is required in terms of data, evidence and evaluation to test interventions for producing “best value for money”?**

The continuation of National Quality Performance Indicators for all cancer types, including brain and CNS tumours are critical to driving improvement in clinical care, and testing interventions aimed at driving earlier and more accurate diagnosis of cancer in Scotland.

In terms of cancer awareness, the HeadSmart campaign’s effectiveness is tested by annual evaluation of data on average diagnosis times for brain tumours in children, teenagers and young people. In addition, as we have highlighted above, the Teenage Cancer Trust’s programmes have been evaluated by the University of Stirling using randomised controlled trials, which have provided robust evidence for the effectiveness of the programme.

Repeating the Scottish Cancer Patient Experience Survey on an annual basis would also help to track the effectiveness of interventions to drive earlier diagnosis of cancer. Last year’s survey tracked the responses of patients across a range of cancer types about the wait before seeing a GP or other doctor for the first time, the amount of times a patient saw a GP about the health problem caused by cancer, and the amount of time that patients had to wait for a diagnostic test. The Survey should also be expanded to include the experience and teenagers and young people under the age of 16.

4. **How can the shift of spending from reactive/acute services to primary/preventative services be speeded up and/or incentivised?**

Reducing the number of cancer diagnoses in emergency admissions is critical to enabling a shift in resources from acute care to primary care. Raising awareness of the signs and symptoms is important to ensure that patients and their families present at an early stage in primary care, are diagnosed earlier and have a greater chance of avoiding expensive treatment in secondary care.

We recommend that all Health Boards should conduct an annual audit of cancer diagnoses so that we can understand the causes behind emergency admissions. The Scottish Government’s commitment to invest £2 million in a new Diagnostics Fund is also an opportunity to shift spending towards primary care settings.

**Recommendations**

1. The Detect Cancer Early programme should be maintained by the Scottish Government, with future campaigns focusing on cancers with low survival, which often have vague symptoms like brain tumours.
2. Adult Neuro-Oncology Networks in Scotland should take action to ensure that Quality Performance Indicators around molecular testing and analysis are met.
3. The Scottish Cancer Patient Experience Survey should be repeated on an annual basis to help measure the success of interventions to drive earlier diagnosis of cancer.
4. All Health Boards should conduct an annual audit of cancer diagnoses so that we can understand the causes behind emergency admissions.

**Bibliography**