

New clinical guidelines and public awareness campaign slash diagnosis time for children's brain tumours

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The UK's performance on diagnosing brain tumours in children and young people has been transformed by new clinical guidelines and a national awareness campaign—taking it from one of the worst ranking countries in the world to one of the best.

In an academic paper published in the journal *Neuro-Oncology*, researchers at The University of Nottingham, who developed the new clinical guideline in 2008 and then publicised its message with the HeadSmart: Be Brain Tumour Aware campaign in 2011, say the campaign is associated with a reduction in diagnosis times from a median of 14 weeks to just 6.7 in its first two years.

HeadSmart is due to be re-launched in 2016 with a focus on increasing

symptom awareness among general practitioners and adolescents in a bid to further reduce diagnosis time to four weeks in line with the standard specified in Achieving World Class Cancer Outcomes – a Strategy for England 2015-2020, which identified the campaign as a programme for evaluation in its strategy to accelerate cancer diagnosis.

World-first in paediatric cancer

Professor David Walker, co-director of the University's Children's Brain Tumour Research Centre and the campaign's leading clinician, said: "This strategy to speed up the diagnosis of [brain](#) tumours by the NHS using an awareness campaign to educate both the public and healthcare professionals is a world-first in paediatric cancer.

"As a result, the campaign is now being emulated internationally and has been acknowledged by a number of NHS and charity awards of excellence."

Brain tumours account for one-quarter of all childhood cancers, affecting one in 2,400 children under the age of 16 annually in the UK. While five-year survival rates have risen to more than 70 per cent, almost two-thirds (60 per cent) of long-term survivors of childhood brain tumours are moderately or severely disabled. Early diagnosis can have a huge impact on the prognosis and long-term effects for these children.

Drive for change

A national survey in 2006 revealed that UK referral practice ranked poorly in international comparisons, resulting in the new NHS referral guidelines published in 2008 by the Royal College of Paediatrics and Child Health (RCPCH).

To support this, the RCPCH worked with the Children's Brain Tumour Research Centre in Nottingham and the Brain Tumour Charity to develop the HeadSmart campaign, which aimed to be a 'driver for change' and to reduce diagnosis times to just five weeks.

The campaign produced a range of awareness materials—including a handy symptom checker—which could be used during consultations. These were distributed directly to healthcare professionals via conferences and seminars and direct mail out to GPs surgeries.

Community champions were enlisted to take the materials directly to the general public through a range of channels including local schools, nurseries, hospital waiting rooms, local authorities, charities and even through a chain of toy shops.

Providing clear information

The open access 'decision support' HeadSmart website offered complementary guidance and links to existing NHS and health-related sites, providing advice on relevant signs and symptoms. It offered clear guidance on which symptoms required timely review or immediate imaging, with the emphasis on reassuring patients and providing information in a clear, accessible way.

Clinical champions at 17 Children's Cancer and Leukaemia Group treatment centres submitted data on 710 patients' dates of symptom onset, dates of initial presentation to healthcare and the dates of diagnosis for both pre- and post-campaign.

The results showed that the median time it took for patients to be diagnosed fell from 9.1 weeks in January to June 2011 (pre-launch) to 6.7 weeks in the second year after the campaign was launched.

In addition, the change in referral practice was most notable in the time it took from first medical contact to the patient being sent for neurological imaging, which reduced from 3.3 weeks to 1.4 weeks.

Increasing confidence

Surveys were used to assess awareness of the campaign and its impact on healthcare professionals. After its launch, 54 per cent of paediatricians said they felt more confident about diagnosing brain tumours compared to a previous 32 per cent while confidence remained low for GPs at just over 10 per cent. Awareness of the HeadSmart materials was again higher among paediatricians (73 per cent) compared to GPs (26 per cent).

Professor Walker added: "We placed the risk of excessive public alarm and the potential for swamping imaging facilities at the top of our risk assessment and designed our materials to prioritise reassurance. We are unaware of any evidence of public alarm or excess imaging referrals and received appreciative feedback from paediatricians who valued the reassuring advice for those children who did not require a brain scan."

The team is carrying out ongoing research to corroborate the findings using population data funded by The Brain Tumour Charity and The University of Nottingham's joint grant funding programme.

Dr Jan Dudley of the Royal College of Paediatrics and Child Health, and Executive of HeadSmart project board said: "The progress made by the HeadSmart campaign in reducing diagnosis times on brain tumours is wonderful to see.

"Brain Tumours remain the leading cause of cancer deaths in children, with approximately 500 children a year diagnosed with a [brain tumour](#). The HeadSmart campaign is, and will continue to have, a huge effect on

many children and families around the UK.

"We still lag behind some of the best performing nations in the time taken for brain tumours to be diagnosed however. The relaunch of the HeadSmart campaign will hopefully see the UK overcome this deficit, making the UK an example of excellence in diagnosis times for brain tumours."

Sarah Mee, head of policy and campaigns for The Brain Tumour Charity, said: "We are delighted that our HeadSmart partnership has proved so effective in reducing the average time it takes to diagnose a childhood brain tumour in the UK.

"Its success has made a real difference to many children and families affected by the disease, who would otherwise have faced longer waits before diagnosis and potentially a worse outcome.

"However, we want to make sure that the average wait is brought down even further, in line with the best-performing countries, in order to help minimise the damage caused by childhood brain tumours. We will continue to work with the Children's Brain Tumour Research Centre and the RCPCH towards that target."

The campaign is due to be re-launched with a focus on raising awareness further among GPs and teenagers, with the aim of reducing diagnosis time again to hit the national benchmark of four weeks.

More information: Achieving World Class Cancer Outcomes – a Strategy for England 2015-2020: www.cancerresearchuk.org/sites/default/files/2015-09/achieving-world-class-cancer-outcomes-a-strategy-for-england-2015-2020.pdf

Provided by University of Nottingham

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