

Institution: University of Nottingham
Unit of Assessment: UoA1
Title of case study: Accelerating diagnosis of the UK's biggest childhood cancer killer
<p>1. Summary of the impact</p> <p>The University of Nottingham's Children's Brain Tumour Research Centre developed new NHS evidence-accredited referral guidelines, published in 2008, to reduce diagnostic delays for children with brain tumours. Their messages were disseminated through an awareness campaign, 'HeadSmart – Be Brain Tumour Aware', launched in 2011. Three months post-launch, 11% of the UK population (over 14 million people) and 73% of paediatricians were aware of HeadSmart, and diagnostic confidence among paediatricians had risen from 32% to 54%. The time from symptom onset to brain tumour diagnosis reduced from 14.4 weeks in 2006 to 6.9 weeks in 2013. This strategy is a 'world first' in paediatric brain tumour, now being emulated internationally.</p>
<p>2. Underpinning research</p> <p>Why children's brain cancer? Brain cancers are the commonest solid tumours for children under 16 years, with around 500 being diagnosed in the UK annually. Delays in diagnosis are common, risking premature death in a few and disability in over 60%, mainly due to brain damage occurring around the time of diagnosis. The risk of disability is greatest for the youngest, due to their brain's immaturity, and can impair a child's acquisition of critical skills, thereby impairing their education. Watch: Jake's Video; Sarah's Video; All they need is a scan</p> <p>Why try to accelerate diagnosis? For patients and families, reducing unnecessary delays at the critical moment of diagnosis is important to boost their confidence in health care, and to improve survival and reduce disability of survivors. As tumours detected earlier are usually smaller, there is less raised intra-cranial pressure, tumour invasion and compression of vital structures, and therefore less brain damage. Symptoms that progress during the pre-diagnostic interval are consequently less advanced, reducing damage to vision, dexterity, mobility, cognition and the brain's control of growth and development.</p> <p>Why did this project happen? The University of Nottingham's Children's Brain Tumour Research Centre (CBTRC) was established in 1997 to initiate research focused upon issues prioritised by children with brain tumours and their families. Public concerns about diagnostic delays, expressed in the media, in the courts and in Parliament, were very prominent and resonated with professional concerns. The median total diagnostic interval (TDI) from symptom onset to diagnosis were reported to be 12.0-14.4 weeks in the UK, whilst comparable figures in the US and Poland were 5 weeks, and Canada, Switzerland and Israel were less than 8 weeks.</p> <p>What research did we do? Professor David Walker, Dr Sophie Wilne, Ms JoFen Liu, Professor Richard Grundy, Ms Maya Sussman (all University of Nottingham, 1993-2013), and Professor Colin Kennedy (University of Southampton), conducted evaluations of regional referral practice in four English centres (1981-2006) and a regional audit of referral practice. Dr Thomas Chu and Professor Michel Coleman (both London School of Hygiene and Tropical Medicine), working with Professor David Walker at the CBTRC, studied referral practice across the primary : secondary care interface using linked data sets from the National Cancer Registry, primary (CPRD, Clinical Practice Research Datalink) and secondary care (HES, Hospital Episodes Statistics) electronic records from 1997-2007 in under 24 year olds. Together, these studies showed that the current median TDI in four English regional units was 14.4 weeks and had not changed over the previous 25 years [1,2]. We found that multiple ineffective referrals between home, primary and secondary care were occurring prior to diagnosis, particularly in patients with the slowest growing tumours. The symptom groups that progressed most during the interval from symptom onset to diagnosis were those involving visual and motor functions. We decided to produce a new clinical referral guideline for the UK, and to develop and run an awareness campaign.</p>

Impact case study (REF3b)

How did we produce the guideline? We conducted a systematic literature review and meta-analysis of previous studies describing symptomatology [3], which, together with information from referral studies, supported a Delphi consensus process with over 150 experienced health professionals and parents. 77 consensus statements were accepted, and supported the AGREE process which was used to draft a new Clinical Guideline.

What methodology underpinned the awareness campaign?

The awareness campaign was managed according to Quality Improvement (QI) methodology, and included:

- Rapid resource development using Plan Do Study Act (PDSA) cycles.
- The selection and application of a QI driver target, a median of 5 weeks which equals the best reported TDI data in the USA, for service change.
- Development of a UK network of **Clinical Champions** in each of the children's cancer treatment centres to communicate the aims and methods of the project with their regional paediatric and primary care colleagues and collect TDI data from each new case of brain tumour prior to and after the Campaign launch.
- A developing network of **Community Champions**, recruited to disseminate the campaign within local communities and media.

3. References to the research

- 1) **Wilne SH**, Ferris RC, Nathwani A and Kennedy CR. The presenting features of brain tumours: a review of 200 cases. Arch Dis Child. 2006 June;91(6):502–506. (Scopus citation 52)
<http://dx.doi.org/10.1136%2Fadc.2005.090266>
- 2) **Wilne S**, Collier J, **Grundy R** and **Walker D** et al, 2012. Progression from first symptom to diagnosis in childhood brain tumours. European Journal of Pediatrics. 171(1), 87-93. (SC 6)
<http://dx.doi.org/10.1007%2Fs00431-011-1485-7>
- 3) **Wilne S**, Collier J, Kennedy C, Koller K, **Grundy R** and **Walker D**. 2007. Presentation of childhood CNS tumours: a systematic review and meta-analysis The Lancet Oncology. 8(8), 685-695 (SC 71)
<http://dx.doi.org/10.1016%2FS1470-2045%2807%2970207-3>

Grants

- 09/2003-02/2006 Walker et al 'Tracking delays in diagnosis of brain tumours in childhood'. Samantha Dickson Brain Tumour Trust / Community Fund (Lottery) £105k
- 09/2006-08/2007 Walker et al 'Pathways II Introduction of guidance to shorten symptom interval' Samantha Dickson Brain Tumour Trust £44,479
- 11/2009 - 10/2011 Walker et al 'Brain Pathways: Promoting an earlier diagnosis of brain tumours in children'. Health Foundation £409k
- 2013-2018 David Walker and Richard Grundy, CBTRC Programme Grant, The Brain Tumour Charity £1.5m (within this, a programme grant £200k awarded for HeadSmart post-doctoral fellowship).

4. Details of the impact

The clinical guideline

The new Clinical Guideline was published by the Royal College of Paediatrics and Child Health (RCPCH), with endorsements from additional relevant colleges in **2008**. It was awarded NHS Evidence accreditation in **2010** [a].

The awareness campaign

In line with recommended practice, we planned a dissemination strategy and acquired funding through a collaborative application involving the Children's Brain Tumour Research Centre (CBTRC), RCPCH and The Brain Tumour Charity (formerly the Samantha Dickson Brain Tumour Trust) to the Closing the Gaps scheme of the Health Foundation. The strategy was designed to reduce multiple referrals by highlighting symptom clusters in a handy symptom card for the public

Impact case study (REF3b)

and profession, and by signposting to a decision-support website (www.headsmart.org.uk/home/). These use evidence-based criteria for **reassurance**, timed **review** and urgent **referral** for imaging. The information support website is linked to relevant NHS websites. Training modules have been developed within the HeadSmart website as well as an additional module [b] developed in conjunction with the Royal College of General Practitioners (RCGP), called 'Brain Tumours in Children' (launched from their e-learning website). There are also Facebook (facebook.com/headsmartcampaign) and Twitter (<https://twitter.com/HeadSmartUK>) profiles, and a smartphone app (Text SMART to 81400).

The dissemination campaign, consisting of symptom cards, website and media programme, was launched on 11th June 2011 to the profession and the public, with political, professional, charity and Department of Health support. Watch: [HeadSmart Launch video](#).

Was awareness and confidence raised?

'The awareness of the signs and symptoms of a childhood brain tumours have dramatically increased since the HeadSmart campaign was launched' [c]. Around 14 million people were made aware of HeadSmart, equating to 11% of the UK population [d]. Over 650,000 symptom checklist cards have now been distributed, the website has had over 117,000 visits from >98,000 unique visitors and is currently (July 2013) experiencing >12,000 visits from >11,000 unique visitors per month, the Facebook site has >12,000 likes and Twitter has >1,250 followers [e]. Professional surveys identified that 73% of paediatricians but only 26% of GPs were aware of HeadSmart after the launch in **2011** [f]. Amongst paediatricians, confidence in making a brain tumour diagnosis rose from 32% to 54% [f]. In July 2013, the RCGP agreed to disseminate campaign materials to its 46,000 membership throughout 2013/14 [g].

Were cases diagnosed more quickly?

Through our clinical guideline and HeadSmart campaign, we 'effectively decreased the risk of serious consequences associated with delay through significantly reducing the time taken to diagnose brain tumours in children from 13 weeks to 6 weeks' [g].

Comparing total diagnostic interval (TDI) data at 3 time points:

- 1) In **2006** in 4 centres for one year,
- 2) In **Jan-June 2011** after Guideline publication in **2008** and prior to HeadSmart launch;
- 3) Post HeadSmart launch until **May 2013**.

There was a 52% decrease ($p=0.001$) in median TDI across these three time points, with a 65% decrease (3 weeks to 1 week) in median time from first doctor contact to brain scanning. These decreases in median TDI had the greatest impact in low grade tumours, compared with high grade tumours, and a trend for centrally placed tumours involving optic pathways compared with other

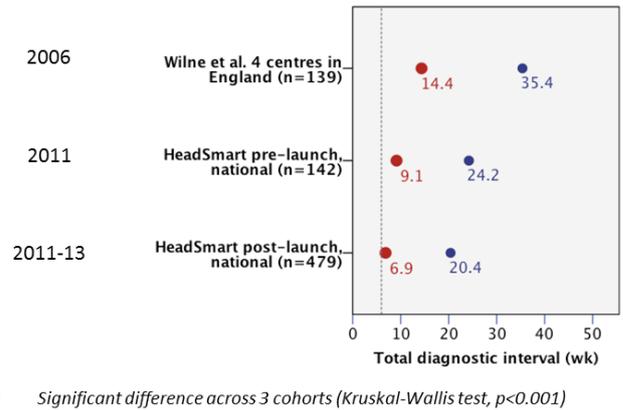
The screenshot shows the HeadSmart website interface. At the top, the logo reads 'HEADSMART be brain tumour aware'. Navigation links include Home, About HeadSmart, Personal stories, How Can I help?, and HeadSmart materials. Social media icons for Facebook, Twitter, and a 'Donate now' button are present. The main content area features three columns for different age groups: 'Under 5 Preschool', '5-11 Children', and '12-18 Young People'. Each column lists symptoms under the heading 'Brain tumours happen... Symptoms include:'. Below these columns, there is a section for 'Additional symptoms to be aware of' which includes 'Reduced consciousness', 'Diabetes insipidus (excessive drinking and urination)', and 'Abnormal growth'. At the bottom, there are three boxes for 'Additional information for healthcare professionals', 'Additional information for parents and carers', and 'Additional information for teens and young people', each accompanied by a small image of a person.

Impact case study (REF3b)

anatomical sites. The fall in TDI began with the publication of our clinical guideline in 2008 [g,h], and HeadSmart built on this, ‘the time to diagnosis being dramatically reduced from 9.2 to 6.9 weeks in just two years, summing up the remarkable impact of this campaign’ [c].

Figure: Time from symptom onset to brain tumour diagnosis has been reduced from a median/mean of 14.4/35.4 weeks (2006) to 6.9/20.4 weeks (2011-2013).

Total Diagnostic Interval (wk) – UK Multi-centre Studies



Our preliminary findings on 1 year survival, disability rates, visual impairment rates, public and professional awareness and website

usage, are the focus of on-going evaluation until 2016, whilst the awareness campaign is sustained and augmented. As a result of our lobbying, the National Cancer Intelligence Network announced in 2012 that it will collect TDI data from children with a brain tumour as part of the cancer registry dataset from August 2013 [i]. This will benefit researchers and clinicians nationally, and also facilitate our ongoing evaluation of the impacts of HeadSmart.

This strategy is a ‘world first’ in paediatric brain tumour, now being emulated in Germany, Denmark, Sweden, Italy and Iran [g,j]. Its excellence was acknowledged by an NHS Innovation Award in **2013**, worth £100,000. As summarised by the RCPCH ‘Overall, this is an excellent piece of work with wide professional and societal impact and has helped ensure speedier diagnosis for children with complex conditions as part of optimising clinical practice’ [h].

5. Sources to corroborate the impact

- a. Sophie Wilne, Karin Koller, Jacqueline Collier, Colin Kennedy, Richard Grundy and David Walker (2010) The diagnosis of brain tumours in children: a guideline to assist healthcare professionals in the assessment of children who may have a brain tumour. Archives of Disease in Childhood. 95, 534-539. (SC 18): <http://dx.doi.org/10.1136/adc.2009.162057>
- b. RCGP Training: <http://www.elearning.rcg.org.uk/course/info.php?id=99>
- c. Letter from Neil Dickson, Founder and Vice-Chair, The Brain Tumour Charity.
- d. Media impact report: <http://www.cbtrc.org/cbtrc/headsmart/index.aspx>
- e. HeadSmart dissemination summary. Google analytics: HeadSmart website traffic data. Provided by Peter Dickens, Head of Communications, The Brain Tumour Charity.
- f. The Health Foundation report (also available as a pdf on request): <http://www.health.org.uk/public/cms/75/76/6270/3930/CtGtCC%20HeadSmart%20final%20report.pdf?realName=UT94qs.pdf>
- g. Letter from Dr Jane Jones, Assistant Director, The Health Foundation.
- h. Letter from Dr Chris Harvey, Chief Executive, Royal College of Paediatrics and Child Health.
- i. NCIN evidence of NCIN changing strategy to collect TDI data: <http://www.ncin.org.uk/view?rid=1761> (see first 2 bullet points on slide 9)
- j. Letter from Kathy Oliver, Co-Director, The International Brain Tumour Alliance.