



## Closing the Gap through Clinical Communities



Formerly, The Brain Pathways Project



## Final Report for Closing the Gap through Clinical Communities

**Project Title:** HeadSmart - be brain tumour aware

**Lead Organisation;** HeadSmart is a collaborative project between three organisations; Samantha Dickson Brain Tumour Trust, the Royal College of Paediatrics and Child Health and the Children's Brain Tumour Research Centre at the University of Nottingham.

### Partner organisations

**Royal College of Paediatric and Child Health (RCPCH)** is the medical body responsible for the education and training of paediatricians, and setting and promoting high standards of clinical practice. The project is managed at RCPCH. <http://www.rcpch.ac.uk/>

**University of Nottingham Children's Brain Tumour Research Centre (CBTRC)** is a multi-disciplinary team of leading healthcare professionals and researchers – all experts in their fields, and all committed to improving our understanding of childhood brain tumours. Professor David Walker, Paediatric Oncologist is the lead clinician on the project. [www.cbtrc.org/](http://www.cbtrc.org/)

**Samantha Dickson Brain Tumour Trust (SDBTT)** is the largest brain tumour charity in the UK, focusing on funding of research and providing support and information to those with brain tumours. It has considerable experience of parents whose children have suffered through late and misdiagnosis of brain tumours, and in 2004 began a partnership with Professor David Walker, HeadSmart's lead clinician, to investigate this further. The 'Diagnosis of Brain Tumours in Children' guidelines are the result of the long-term partnership that has been developed. <http://braintumourtrust.co.uk/>

### Lead Clinician

**Professor David Walker** is a Professor of Paediatric Oncology at the University of Nottingham (UoN), a Fellow of the Royal College of Paediatrics & Child Health (FRCPCH) and the lead clinician and fundholder of the HeadSmart project. He helped develop the Children's Brain Tumour Research Centre as a research grouping and led the early phases of this project in collaboration with the Samantha Dickson Brain Tumour Trust. He has previously been involved in leading clinical trials in children's brain tumours in the UK and Europe, and is currently involved in the All Party Parliamentary Group on Brain Tumours. Professor Walker is an acknowledged leader in this field, and an expert in the clinical factors affecting diagnostic processes in brain tumours and is held in high regard in his specialist area.

**Dr Sophie Wilne** is a consultant paediatric oncologist working for the East Midlands Children's and Young Person's Cancer Service who has also been pivotal to the project's success. She has expertise in the processes of systematic reviews, guideline development and implementation, which have aided her involvement in developing the HeadSmart website and materials.



## **Abstract:**

**HeadSmart Be Brain Tumour Aware** (formerly Brain Pathways) has developed a public and professional awareness campaign aimed at converting the previous symptom interval for children presenting with brain tumours, from onset to diagnosis, of 3 months previously, into 1 month as a national target for the UK. This target was set after public concern had been expressed in the media, Parliament and with the Samantha Dickson Brain Tumour charity; a previous research programme had identified that the UK was slower than other countries; a new set of clinical guidelines were developed to enhance clinical guidance, which have been since been endorsed by NHS Evidence. This expression of concern and the clinical guidance and its evidence base justified and underpinned the HeadSmart Campaign. Quality Improvement drivers were set, focussed upon measuring symptom interval, engaging with clinical and community champions, creating a decision support website and targeting the launch of an awareness campaign to the profession and the public. This programme was supported by, and contributed to, DH, NICE and professional policy. A health economic programme has been initiated.

The HeadSmart campaign has been successful in raising awareness of symptomatology by doctors seeing children and enhancing their confidence in making the diagnosis of brain tumour. In surveys taken 4 months after the launch in June 2011, 11% of the public were now aware of the campaign. The Clinical Champions in cancer units have measured symptom interval over the past year and shown a significant reduction from pre-campaign levels. The confidence and awareness of GPs has not yet been fully evaluated. We are awaiting NICE Cancer Referral Guidance review, which would prioritise this for GPs. A sustainability programme has been initiated and further funding secured and an associated research programme is in development. There are two major focuses for this phase of the campaign: to change expected symptom interval in the profession's minds from **3 into 1** month. We believe that this change in professional perception will be highly instrumental in driving on-going change in clinical practice; secondly, to ensure that families across the socio-economic spectrum are aware of and have access to information on the signs and symptoms.

### **1.1 The Quality Challenge Background Knowledge**

#### **Significance of the Health Issue and Gaps in Clinical Quality**

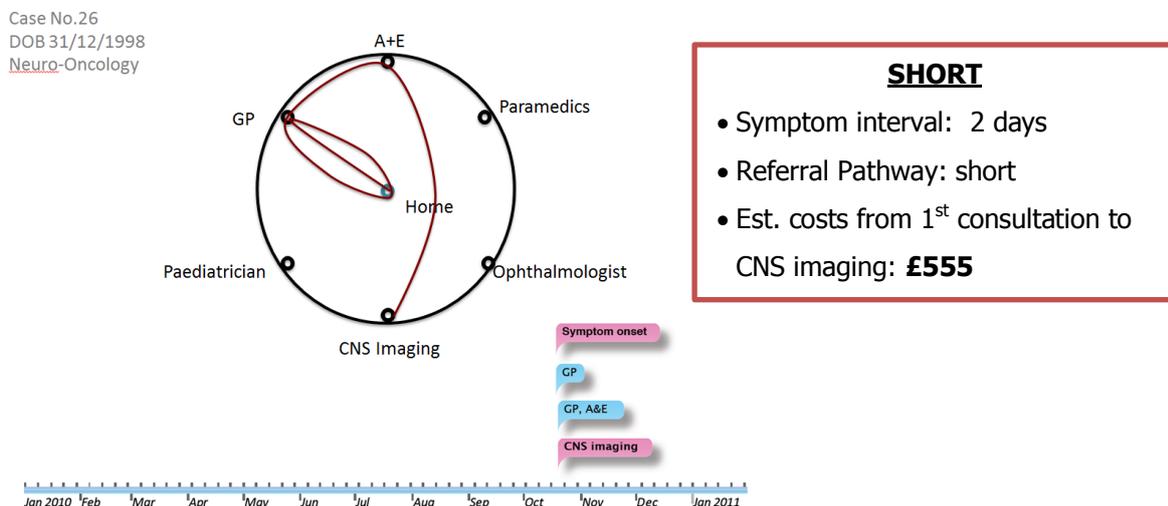
**The gap in clinical quality** was that there had been repeated reports of professional, parental and patient concern in the media that UK health systems were failing to make the diagnosis of brain tumour in a timely fashion (<http://www.headsmart.org.uk/personal-stories/>). This

constitutes a significant **health issue** as brain tumours account for quarter of all childhood cancers, affecting 1 in 2,400 children under 16 years, putting nearly 32,000 life-years at risk every year. More children die of brain tumours than any other cancer accounting for the loss of 10,000 life-years each year. The rising number of long term survivors of childhood brain tumours experience ten times the disability of well children and often require state and family support throughout adulthood accounting for the gain of 20,000 disabled life-years, every year.

UK children are often unwell for several months prior to diagnosis. The median time between symptom onset and diagnosis (symptom interval) experienced by UK children is between two and three months; this is up to three times longer than that experienced by children in Canada and the USA. Children often present as an emergency and extremely unwell, which increases the risks of death or severe disability at the time of surgery. Independent of surgical risks, a prolonged symptom interval is also associated with increased long term neuro-cognitive disability and visual impairment.

**Statistic: 59% of teenagers with brain tumours visited their GP four or more times with symptoms before referral.**

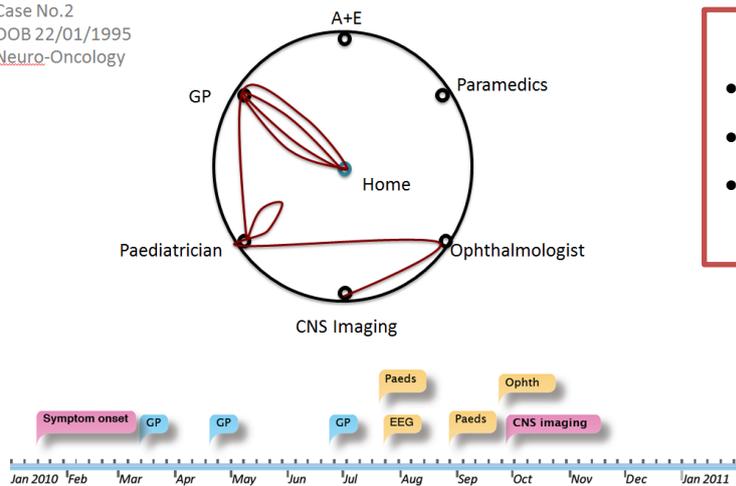
In an earlier audit project, conducted in 2010, we used the "handoff diagram(s)" to illustrate the healthcare attendances (lines) and time to diagnosis (scale) to CNS imaging. These activities were also linked to National Schedule of Reference Costs Year 2010-11 to estimate costs from first symptom onset to CNS imaging. Although there were some limitations of the methods (e.g., recall error), it is clear that the interval between first symptom to diagnosis, referral pathways and service costs vary significantly in paediatric brain tumour patients (Figures 1-3)<sup>1</sup>.



**Figure 1:** An example of short symptom interval and direct interval. Patient was seen by GP twice within 48 hours and was referred to A&E immediately; CT scan was done on the same day.

<sup>1</sup> Maya Sussman (2010). *Neurological referral in paediatrics: an audit of referral pathways for common neurological conditions.* BMedSci Dissertation, University of Nottingham.

Case No.2  
 DOB 22/01/1995  
 Neuro-Oncology

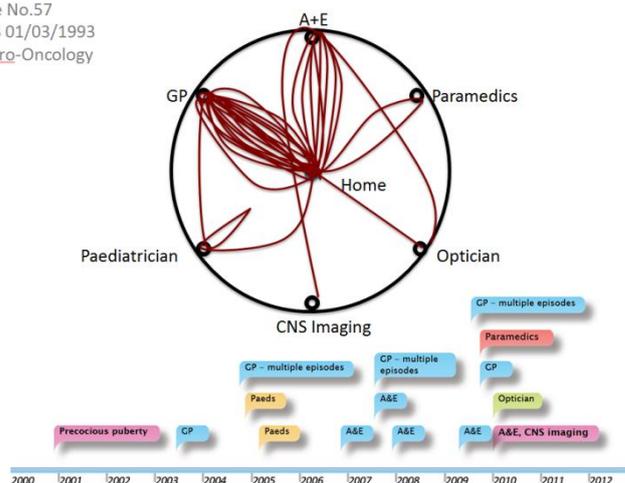


**MEDIUM**

- Symptom interval: 8.4 months
- Referral Pathway: medium
- Est. costs from 1<sup>st</sup> consultation to CNS imaging: **£1,280**

**Figure 2:** An example of patient with medium symptom interval and referral pathway. Patient was referred to secondary care for opinion because of additional symptoms and increased severity. MRI scan took place in September 2010, about 6 months after first GP consultation or 8.4 months after first symptom.

Case No.57  
 DOB 01/03/1993  
 Neuro-Oncology



**LONG**

- Symptom interval: 9 years
- Referral Pathway: long
- Est. costs from 1<sup>st</sup> consultation to CNS imaging: **£3,535**

**Figure 3:** An example of delayed referral. Parents noticed the first symptom of early puberty in late 2000, a significant number of healthcare professionals were involved in the pathways but the patient was not diagnosed until 2010. A formal complaint was issued to the primary care trust after the diagnosis.

At the time of applying for this award we had published *Diagnosis of Brain Tumours in Children: A guideline* which was endorsed by the Royal College of Paediatrics Child Health (RCPCH) in 2008. A systematic review of the world literature on the symptom intervals for children with brain tumours compares published UK data regarding the interval from symptom onset to diagnosis (symptom interval) unfavourably with other international reports (Figure 2).

We proposed a project focused upon enhancing public and practitioner awareness, promoting timely access to brain scanning using evidence based guidelines in order to promote self referral,

enhanced access to high quality information and expert diagnostic support systems, so as to assist with selection of patients for imaging, observation or reassurance.

## **1.2 The Local Problem and context**

### **Environment**

#### **The interface between primary and secondary care**

The process of diagnosing neurological signs and symptoms in infancy, childhood and adolescence requires the parent or child (<18 years) to acknowledge there is a health problem and then seek a consultation with either a primary care or emergency doctor who accepts the need for referral or investigation and initiate a plan commensurate with the seriousness of the differential diagnosis, before the diagnosis is clear. If the problem is a brain tumour, the shock of the diagnosis to the child and family inevitably precipitates a biased and frequently critical review of events leading up to diagnosis.

### **Organisation**

#### **UK scope**

The evidence upon which our innovation was to be deployed was based upon UK data, justifying a UK-wide approach. Children's cancer services were already linked to an established UK network of centres, with brain tumour centres being clearly identified. The further refinement of this network was in process through the NICE Implementation of Cancer Guidance and Peer Review process 2005-2011 in England and similar arrangements in Scotland (SIGN), Wales and Northern Ireland had already been developed. The UK Children's Cancer and Leukaemia Group (CCLG) had previously worked closely with cancer centre(s) in Eire and so the project was extended to the Republic of Ireland.

### **Policy**

In England the project met the priorities of policy for children as specified:

- 'Equity and Excellence, Liberating the NHS' (July 2010)
- "Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs" (Kennedy 2010)
- "Achieving Equity and Excellence for Children" (DH 2010)
- "Improving Outcomes: A Strategy for Cancer" (DH Jan 2011)
- "Delayed Diagnosis of Cancer: Thematic Review" (NPSA / RCGP 2010)
- National Awareness and Early Diagnosis Initiative (DH 2011)
- Brain Tumour manifesto of the All Party Parliamentary Group on Brain Tumours (October 2010) [www.braintumourtrust.co.uk/manifesto](http://www.braintumourtrust.co.uk/manifesto)
- Detect Cancer Early Initiative - Stakeholder Engagement – Scotland (2011)
- Together against Cancer – Wales (Dec 2011)

### **Stakeholders**

The project team had already identified stakeholders with interest in the Guideline and its implementation which included:

- Relevant professional colleges
- Brain tumour charities
- Department of Health (DH)
- National Awareness and Early Diagnosis Initiative (NAEDI)
- National Institute for Clinical Excellence (NICE)

- Guideline and Implementation Network (GAIN)
- Scottish Intercollegiate Guidelines Network (SIGN)
- Children's Cancer & Leukaemia Group (CCLG)
- Celebrity ambassadors
- Clinical and patient champions

### **Targeting Innovation**

The innovation proposed was to be targeted at the interface of primary and secondary care. Previous published regionalised data, from the last two decades had identified a stable recorded symptom interval unaffected by the publication of relevant NICE Cancer Referral Guidelines, incorporating children's brain tumours in 2005. The project team proposed an awareness-raising approach to the public and profession, backed by a decision-support and training website, complemented by an evaluation programme, driven by Quality Improvement methodology for system development and driver targets.

### **1.4 Intended Improvement**

The project was aimed at:

- **reducing** the average time to diagnose children (<18 years) with brain tumours in the UK from 13 weeks to 6 weeks
- **disseminating** the content of Diagnosis of Brain Tumours in Children: A guideline to the profession and highlighting the symptomatology and awareness of the risk to the public
- **complying** with and influencing national policy on children's priorities and early diagnosis of cancer
- **developing** a decision-support and professional training website
- **promoting** an awareness campaign directed at empowering the public and providing information to health care professionals
- **evaluating** the impact of the campaign upon public and professional awareness and changes in the symptom interval.

**Figure 4: Driver Diagram**

**What are we trying to accomplish?**

**Describe Project:**

- \_\_\_ Redesign existing/process/service
- \_\_\_ Design new product/process/service
- X Improve system as a whole

X Collaborate and share an existing working improvement to diffuse the innovation

**Brief Description:** What/How

We aim to decrease the current symptom interval from 12 weeks to 5-6 weeks by October 2012

**Measure(s):**

To use data of interval periods from all the units in the country and set up an spc chart

**Funder:** Health Foundation

**Core Team Members:**

- David Walker
- Sarah Lindsell
- Jan Dudley
- Monica Lakhanpaul
- Maureen Baker
- Lucie Clough
- Julia Trusler
- Sophie Wilne
- JoFen Liu

**How do we know a change is an improvement?**

**Change concepts to consider**

**Questions to consider**

<p><b>Objective 1:</b> Develop measures for outcome Measure(s): Symptom Interval period is the key measure and baseline is being developed</p>	<p>All units to be asked for prospective data  Set up data bank / spreadsheet</p>	<p>Need to work out if the units can collect data  Definition of symptom period</p>
<p><b>Objective2:</b> Activate and engage the clinical neuro oncology units  Measure(s): Qualitative surveys</p>	<p>Hold Learning Set 1 in January  Hold Learning Set 2 in April  Hold Learning Set 3 in July</p>	<p>Test different formats for the meeting Buy in from units Develop launch package – product for change Test product</p>
<p><b>Objective 3:</b> Develop Awareness campaigns for GPs  Measure(s): Developing qualitative</p>	<p>Set up engagement meetings Develop and test materials Develop packs for education Disseminate through local networks</p>	<p>Test in one area with set of GPs Build on local connections Beware of risk of current changes</p>
<p><b>Objective 4:</b> Develop Awareness campaigns for paediatricians  Measure(s): Developing qualitative</p>	<p>Set up engagement meetings Develop and test materials Develop packs for education Disseminate through local networks / Royal Colleges</p>	<p>As above</p>
<p><b>Objective 5:</b> Activate the public  Measure(s): Qualitative surveys</p>	<p>Develop materials Develop and test materials Pilot in regions Evaluate Spread</p>	<p>Need to test the cards Need to look at website development and whether it will work Consider all modalities</p>

We selected symptom interval as the driver for change as it encompassed the overall purpose of the Guideline from the patients' and families' perspectives. We predicted that if we selected an ambitious target, measured it and shared it with the profession and the public, it would drive service change through enhanced awareness leading to service redesign driven by adjusted expectations of performance.

### **Clinical Engagement and Team Working**

**The HeadSmart Project Board** was strongly supported by experts in the fields of Paediatric Neurology (Colin Kennedy), Neuro-oncology (David Walker, Sophie Wilne, Richard Grundy), Community Paediatrics (Monica Lakhanpaul), General Practice (Maureen Baker) and Child Health Policy (Monica Lakhanpaul). The Board was chaired by a senior representative of the RCPCH (Jan Dudley), the RCPCH employed the Project Manager (Lucie Clough). We benefitted from QI training and support from Peter Lachman and project support from Berkshire Consultancy (Ian Phillips).

The Clinical Lead (DAW) and Deputy Clinical Lead (SW) as well as the charity, SDBTT, had been involved in the forerunner project called Brain Pathways since 2003, which had done the research justifying the Guideline, developed the Guideline and launched it through the RCPCH and associated stakeholder Colleges and organisations.

### **Factors Hindering Work**

- Rarity of childhood brain tumour
- Risk of raised awareness enhancing public anxiety
- Containing the projects team's ideas to the scope of work agreed.
- Time and budget constraints

### **Factors supporting the work**

- Project management methodology (Prince 2), specifying team roles
- Integration of project objectives with health policy for children and early diagnosis in DH and professional organisations
- Brain tumour charities' support
- Support from the public
- Media interest
- Committed Board Members from relevant key organisations
- Recruitment of external agencies, PR and website development company
- Strong clinical engagement

### **1.3 Changes along the way**

The original bid referred to both brain tumours *and* spinal tumours; we excluded spinal tumours as these did not appear in the guideline.

Selecting "symptom interval" as opposed to "public and professional awareness" as the measurable output for the campaign focus changed the emphasis and priority but not the design of the intervention.

An opportunity to apply for NHS Evidence Accreditation of the Guideline was identified early. This was not outlined in the original bid. An application resulted in accreditation in 2011. This enhanced the status of the Guideline and associated resources.

The Guidelines have also been submitted to NICE Cancer Referral Guidelines review process with the intention of influencing the NICE Referral Guidelines, thereby justifying the adoption of the principles of the Guideline as the recognised standard for GPs.

Collection of symptom interval data was identified as a priority for cancer registration processes. Sophie Wilne has participated in National Cancer Intelligence Network discussions to promote this as standard for the revised cancer registration processes.

Selecting the Clinical Champions in the regional cancer centres, who were in the position to collect the symptom interval data "real time", created a situation where we could look at a measure of referral performance within the year nationally and regionally. This change in focus was driven by the Closing the Gap QI consultation and training processes.

Funding limitations justified piloting campaign materials in the East Midlands so as to assess their acceptability and efficacy (PDSA cycle). We targeted the national audience through radio, TV, social media and a variety of publications.

The anticipated low response rate of planned public surveys methods justified contracting GFK NOP (National Opinion Poll) whose methodology would guarantee representative survey across the UK.

Initial plans to perform a Health Economics systematic literature review as the main product were suspended as the amount of relevant literature was low. Contact with the Collaborating Centre for Women and Children's Health in London, health economic advisors, offered an opportunity to develop a Health Economic model of childhood brain tumour diagnosis. This modelling process is on-going. Collaborative relationships with two academic groups working with relevant datasets have been established, which will ultimately permit the first generation model to be developed and tested by June 2012. A systematic literature review has now been commissioned by CBTRC

We were aware of the risk of raising public anxiety and overwhelming diagnostic capacity for children. We engaged with radiology services in the East Midlands to monitor for changes in imaging referral practice.

## **2. Methods**

### **2.1 The Intervention - Describe the intervention you used and its component parts.**

#### **Choosing the intervention**

This project was developed after prolonged professional exposure to patients' stories expressing concern through "whistleblowing", involvement in media reports, discussions at a political level and participation in research activities. These experiences led up to the development of funding applications aimed at generating new research data, harnessing the opinion of professionals for new clinical referral guideline and considering how best to disseminate the content of that guideline into clinical practice.

**After careful consideration, we took the view that although generating new data about referral practice would assist understanding of what is happening on the ground, it would not change practice.**

The early phases of research identified that the rarity of the condition in the general population, coupled with the clinical complexity of the symptomatology in childhood / adolescence, the frequency of reports that concerns were repeatedly disregarded, meant that, whilst a tailored education programme to train all practitioners seeing children in the specifics of paediatric neurological diagnosis would be desirable, it was not achievable and would never be a priority for > 60,000 doctors working in primary and secondary care. Furthermore, the range of referral routes to brain scan was so diverse that the alternative approach to define a single referral pathway development process would not be feasible.

Consequently, we selected an awareness intervention to empower the public and inform the profession in the expectation that, if the patient and their family's awareness of symptoms and risk were enhanced by supporting information (symptom card and website), they would be empowered to express their concerns to the doctor in a positive way, seeking their guidance. If the doctors' awareness was enhanced and supported by a decision support system, available at the time of consultation, the doctor would be guided to select patients for either **referral**, **review** or **reassurance** and the number of futile repeat attendances would be reduced, shortening the time to diagnosis.



**Figure 5:** Use of symptom card in child and family consultation

### Context

The HeadSmart Be Brain Tumour Aware campaign has adopted the priorities described in the following documents:

- 'Equity and Excellence, Liberating the NHS' (July 2010)
- "Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs" (Kennedy 2010)
- "Achieving Equity and Excellence for Children" (DH 2010)
- "Improving Outcomes: A Strategy for Cancer" (DH Jan 2011)
- "Delayed Diagnosis of Cancer: Thematic Review" (NPSA / RCGP 2010)
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- Brain Tumour manifesto of the All Party Parliamentary Group on Brain Tumours (October 2010) [www.braintumourtrust.co.uk/manifesto](http://www.braintumourtrust.co.uk/manifesto)

## **The Intervention**

The HeadSmart intervention was based upon the successful Meningitis Campaign where a credit card sized clinical guide was distributed widely to the public and professionals (refer to appendices to see symptom card). HeadSmart had the evidence for the guide, its complexity however justified a decision-support website in addition. The card directed the public and practitioner to the website which was designed to meet the different needs of both groups.

Our aim was to provide information for **reassurance**, **review** and **referral**. The need for targeted reassurance was most important as public anxiety in this area of practice could be destructive and evidence of redundant referral practice meant that an improvement could be achieved, without such a risk (see Figs 1-3).

To achieve the acceptance of these interventions, it was important to ensure that the guidance was acceptable to the profession and the public. Acceptability from the professional perspective had already been achieved initially with the Guidelines endorsement by the RCPC and other professional stakeholders. The guideline also needed to link to Government policy. Achieving NHS Evidence status was a significant badge of acceptance and its current consideration within the NICE Cancer Referral Guidance Review process, would, if accepted, place the Guideline as a priority for General Practitioners.

The design of the brand and symptom card, advertising materials and clinical guidelines document needed professional approval and development and were subjected to PDSA cycles to achieve this, involving both parents and health professionals. Similarly, the website design and construction went through a series of design iterations evolving in its complexity, enhancing linkage and extending functionality with the invaluable help of public and professional reviews.

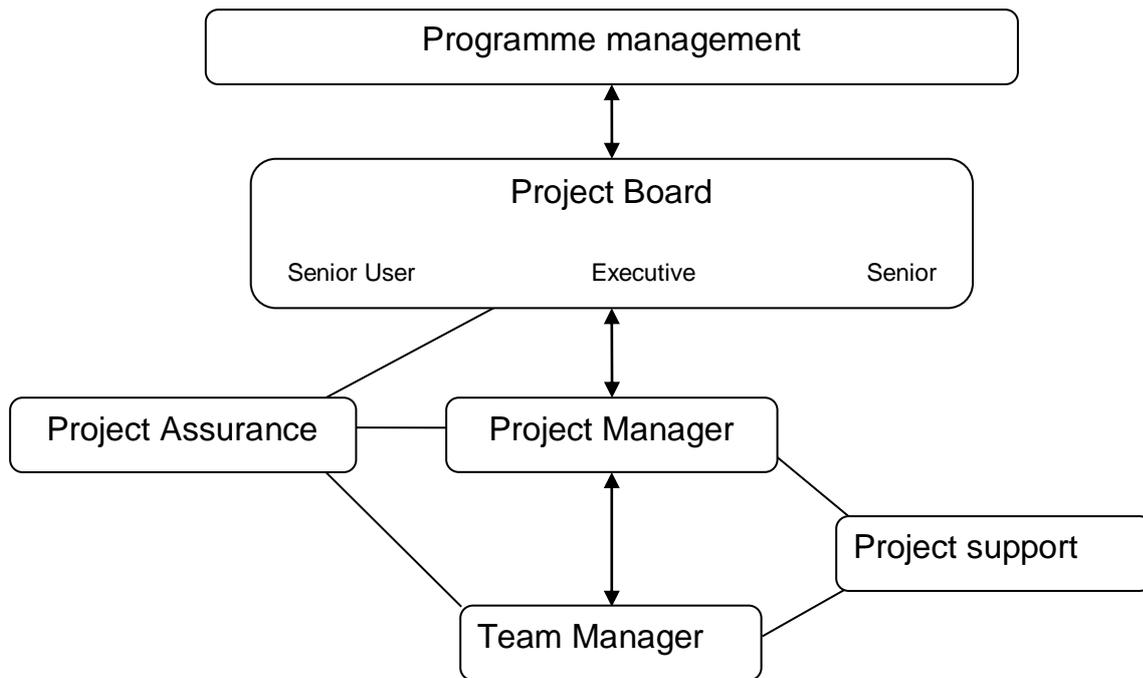
A crucial part of this campaign was the style and nature of the Campaign Launch, the engagement of a PR company for this was critical, combined action by the project stakeholders ensured maximised media coverage. Subsequent to that launch, the Campaign materials were actively disseminated to the national professional organisations through a series of contacts, authored contributions, presentations and regional and national conferences and meetings as well as using social media.

This programme of communication was aimed at maximising engagement with relevant practitioners during 2011/12 (refer to appendices), nationally, and the opportunity was exploited to communicate the programme in Europe and US as a further strategy to enhance outcomes.

Finally, the Campaign required a programme of evaluation so that its impact could be assessed and further guided. Website usage and feedback, public and professional surveys assessing awareness and monitoring of symptom interval of newly diagnosed patients generated data for evaluating the campaign (See Section 3.1 – Outcomes).

## **The Membership and Roles of the Group/Team Leading the Work**

The HeadSmart project team has a breadth and depth of skills including clinicians, policy leads, charity professions who also represented user and patient voices, and quality improvement advisers. Additional expertise was brought in through external companies. PR and communications were managed by Luther Pendragon, and website development by OCB Media.



**Figure 6:** Team Roles

**Table 1:** Team members

Name	Job Title/Organisation	Role in project
Jan Dudley	RCPCH	Executive
Dr Maureen Baker	RCGP representative	Senior User (General Practice)
Paul Carbury (Yr1)/ Sarah Lindsell (Yr2)	Chief Executive, Samantha Dickson Brain Tumour Trust (SDBTT)	Senior User (Patient/carer representative) and campaigning expertise
Julia Trusler	Head of Research, Samantha Dickson Brain Tumour Trust (SDBTT)	Senior User (Patient/carer representative) Senior Supplier – printed and web resource development, campaign expertise
Professor David Walker	Professor of Paediatric Oncology, Children’s Brain Tumour Research Centre, University of Nottingham	Senior Supplier (Lead Clinician) - supplier of guidelines and data relating to early diagnosis upon which the project is based
Professor Colin Kennedy	Professor of Paediatric Neurology University of Southampton	Senior Supplier – supplier of specialist diagnostic expertise, guidelines and historical data
Monica Lakhanpaul	Lead Supplier	Supplier of Policy knowledge and website development

Dr Sophie Wilne	Children's Brain Tumour Research Centre(CBTRC), University of Nottingham	Previous project worker and principal author of guidelines. Quality Assurance Lead Clinical advisor to project evaluation/impact analysis.
Lucie Clough	Project manager Based at RCPCCH, Honorary Contract University of Nottingham	Day to day management of the project, answerable to the Project Board
Jo-Fen Liu	Research Co-ordinator, Children's Brain Tumour Research Centre(CBTRC), University of Nottingham	Epidemiologist - technical co-ordinator of project evaluation/impact analysis

## 2.2 Measurement

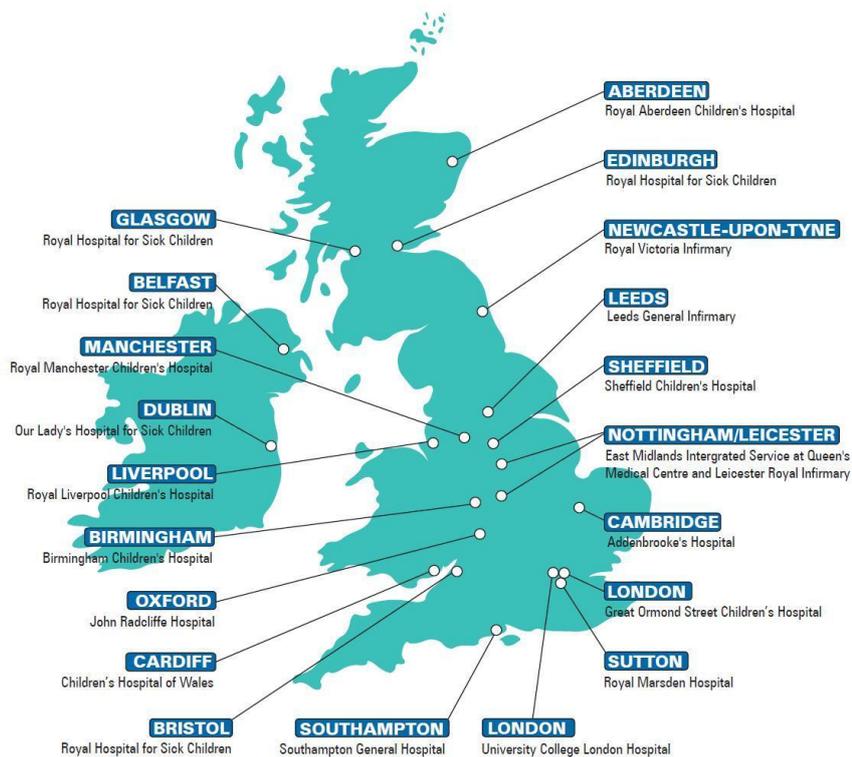
The overall objective of the HeadSmart project is to reduce delays in diagnosis experienced by children and young people diagnosed with brain tumours in the UK. Reducing delays in diagnosis should reduce long-term morbidity and may reduce mortality. Benefits on long-term morbidity will only become apparent after this project has finished and any effects on mortality are likely to be too small to provide a reliable measure of success. We therefore chose to assess the impact and outcomes of HeadSmart by measuring the symptom interval of children newly diagnosed with a brain tumour in the UK and by measuring the awareness of both the public and healthcare professionals of symptoms and signs that can be caused by brain tumours and, after the official launch, of the HeadSmart campaign. Subsequent to campaign launch we have also monitored website hits, campaign interactions via social media and the interactions of community champions in distribution of resources.

### Symptom interval measurement:

Clinical champions were recruited at each of the UK children's cancer and leukaemia primary treatment centres and asked to provide data on the following for each child newly diagnosed with a brain tumour at their centre from January 2011:

- Date of onset of symptoms attributable to the tumour
- Date of initial presentation to healthcare with these symptoms
- Date of tumour diagnosis

Additional information has also been collected on tumour diagnosis, route to diagnosis (emergency / outpatient / inpatient) and signs and symptoms at diagnosis and at symptom onset. Data was recorded using a web-based survey. Champion engagement was encouraged by regular feedback.



**Figure 7:** Children's Cancer & Leukaemia Group Treatment Centres

### Public awareness

A face-to-face omnibus computer assisted personal interview survey was undertaken in February 2011 (prior to campaign launch) and in October 2011 (after campaign launch). The survey determined participants contact with children and young people, awareness of symptoms and signs that could be caused by a brain tumour and the time span with which they thought these symptoms required medical review. The post-launch survey also determined participants' knowledge of the HeadSmart campaign. Ethical approval was granted by the University of Nottingham Medical School Ethics Committee.

### Professional awareness

A web-based survey was distributed via paediatric, emergency and general practice networks to determine pre and post the HeadSmart launch:

- Practitioners' awareness of symptoms and signs that could be caused by a brain tumour
- Practitioners' confidence in their ability to recognise when a child might have a brain tumour

The post-launch survey also determined practitioner's awareness of HeadSmart and their current and potential use of HeadSmart materials.

### Website

Google analytics has been used to analyse website hits, and social media interactions have also been assessed. From 8-15 June 2011 we had 7,866 hits on the HeadSmart website. From 16 June 2011 – 29 March 2012 we have had 11,514 hits.

## Results

### 3.1 Outcomes

1. Primary outcome measures of HeadSmart were:
  - Public awareness of symptoms and signs of childhood brain tumours and the HeadSmart campaign
  - Professional awareness of symptoms and signs of childhood brain tumours and the HeadSmart campaign.
  - The symptom interval (SI) experienced by children newly diagnosed with a brain tumour at UK Children’s Cancer and Leukaemia Group (CCLG) treatment centres
  - The health economic implications of the HeadSmart Campaign
  
2. Secondary outcome measures include:
  - Website hits and clicks through to subsequent pages, breadth of print and broadcast media coverage
  - Recognition of the HeadSmart campaign in healthcare policy and strategy
  - Presentation of the HeadSmart campaign at national and international meetings
  - Publication of information about HeadSmart in public and professional literature

*Measurements of impact upon mortality or disability status and many of the anticipated benefits will be demonstrated beyond the life of the project. These will be monitored by the project team and we would be please to continue reporting these in the future.*

### Public Awareness

Public awareness surveys (Appendix 3) allowed us to assess the current levels of awareness of symptoms and signs of brain tumours in the public, and provided baseline data prior to campaign launch.

The baseline public awareness survey took place prior on 10th – 15th and 17th– 22nd February 2011 and was undertaken by GFK NOP. The response rate was 59%, **647** (129 from East Midlands) completed the survey. (Appendix 5)

A follow up awareness survey took place between 15- 20 September 2011 and 6 - 11 October 2011. The response rate was similar at 56% - **648** (120 from East Midlands) people completed the follow-up survey

**Table 2:** Key results of the pre-launch public awareness baseline surveys (February 2011) and post launch follow-up survey (September/October 2011).

PUBLIC SURVEY	Baseline Results	Follow Up Results (post launch)
<b>Sources of medical information if worried that a child might have serious condition</b> <i>(Multiple responses question percentages do not add up to 100%)</i>	GP: 64% NHS Direct telephone helpline: 43% NHS Direct website: 32%  About 42% of the respondents would speak to friends/ relative/ parents/ guardian	GP: 56% NHS Direct telephone helpline: 36% NHS Direct website:27%  About 40% of the respondents would speak to friends/ relative/ parents/ guardian

<p><b>Length of time before public would make an appointment to discuss high risk symptoms with a doctor</b></p> <p><i>(a list of high symptoms by age group was provided)</i></p>	<p>Over 70% of the respondents would seek medical advice on all symptoms except late puberty and/or slow growth within 2 weeks</p> <p>Funny eye movements, lethargy and poor balance were not deemed as urgent as other symptoms</p>	<p>Over 70% of the respondents would seek medical advise on all symptoms except late puberty and/or slow growth within 2 weeks</p> <p>Funny eye movements, lethargy and poor balance were not deemed as urgent as other symptoms</p>
<p><b>Percentage of public that are aware of the number of brain tumour incident cases (informed that it is 500 cases a year)</b></p>	<p>40-50% said higher than expected</p> <p>16% said less than expected</p> <p>33% said about what they expected</p>	<p>NA</p>
<p><b>Percentage of public that were aware of warning signs of brain tumours</b></p>	<p><b>High Awareness (identified by &gt;80% of respondents)</b> Vomiting, headaches, seizures and vision problems.</p> <p>50%-79% thought deterioration in balance and behaviour change were a warning sign</p> <p><b>Low Awareness (identified by &lt;50% of respondents)</b> Abnormal head position 46% Lethargy 45% Late puberty/ slow groth14% Excessive thirst 12% Passing a lot of urine 11%</p>	<p><b>High Awareness (identified by &gt;80% of respondents)</b> Vomiting, headaches, seizures and vision problems</p> <p>50%-79% thought deterioration in balance and behaviour change were a warning sign</p> <p><b>Low Awareness (identified by &lt;50% of respondents)</b> Abnormal head position 44% Lethargy 46% Passing a lot of urine 9% Excessive thirst 13%; Early or late puberty/slow growth 13%</p>
<p><b>Percentage of those surveyed that had heard of HeadSmart be brain tumour aware?</b></p>	<p>NA</p>	<p>11% of the respondents (71 people) had heard about HeadSmart</p>

### Summary

The levels of awareness were similar at the national and regional level, and there was no significant change in awareness after campaign launch. Both baseline and follow-up surveys showed that the public are least aware of head tilt, lethargy, weight loss, abnormal puberty and diabetes insipidus (excessive thirst and pasting a lot of urine) as potential symptoms of brain tumours. Future awareness campaigns may consider particularly focussing on these symptoms and signs.

**Professional Awareness** (See Appendices 4, 5 and 6)

The baseline survey took place between 21<sup>st</sup> March and 4<sup>th</sup> April 2011. A total number of **323** healthcare professionals took part in the survey. This includes 221 paediatricians, 78 GPs, 4 emergency medicine practitioners, and 17 healthcare professionals from other background (Appendix 6).

The follow-up survey took place 10<sup>th</sup> November 2011 – 3<sup>rd</sup> February 2012. A total of **340** healthcare professionals took part in the follow up survey. This includes 226 paediatricians, 69 GPs, 3 emergency medicine practitioners, and 42 healthcare professionals with other background such as paediatric surgery, oncology, radiology, neurosurgery, haematology, psychiatry and nursing. Key results were summarised on Table 3.2 below.

**Table 3:** Key results of the pre-launch professional baseline surveys (March/April 2011) and post launch follow-up survey (November 2011-February 2012).

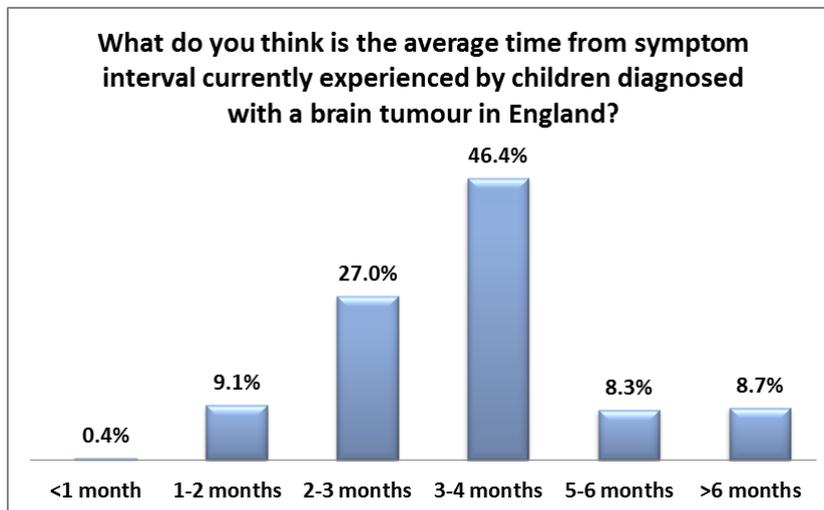
PROFESSIONAL SURVEY	Baseline Results	Follow Up Results (post launch)
<b>Level of confidence in ability to recognise when a child might have a brain tumour</b>	<ul style="list-style-type: none"> <li>• 32% of Paediatricians were confident</li> <li>• 11% of GPs were confident</li> </ul>	<ul style="list-style-type: none"> <li>• 54% Paediatricians were confident</li> <li>• 12% GPs were confident</li> </ul>
<b>View on the average symptom interval of children in the UK</b>	<ul style="list-style-type: none"> <li>• 46% of respondents thought 3-4 months</li> <li>• 17% thought 5 months or longer</li> </ul>	
<b>Respondents' opinion on the statement</b>  <i>"A prolonged symptom interval in childhood brain tumours is associated with worse outcome"</i>	<ul style="list-style-type: none"> <li>• Increased cognitive deficits – 97.6% agreed</li> <li>• Visual loss - 94% agreed</li> <li>• Endocrinopathies - 87% agreed</li> </ul>	<ul style="list-style-type: none"> <li>• Increased cognitive deficits – 96.5% agreed</li> <li>• Visual loss – 95.3% agreed</li> <li>• Endocrinopathies 91.2% agreed</li> </ul>
<b>Symptoms which could be a sign of a childhood brain tumour</b>  <i>(Identify from a list of 15 symptoms; may or may not be specifically related to brain tumour)</i>	<ul style="list-style-type: none"> <li>• Over 95% of GPs and paediatricians thought headache, vomiting, seizures could be potentially indicative of brain tumour</li> <li>• Only 53% of GPs thought abnormal head position could be a sign compared to 84% of paediatricians.</li> </ul>	<ul style="list-style-type: none"> <li>• Over 95% of the GP and paediatricians identified headache and/or vomiting, deterioration in balance or coordination, change in behaviour, seizures or fits, visual abnormalities as indicators of brain tumour.</li> <li>• Only <u>53%</u> of the GPs recognised <u>abnormal head position</u>, compared with 98% in paediatricians.</li> </ul>
<b>Respondents' opinion on " children with brain tumours have multiple signs and symptoms"</b>	<ul style="list-style-type: none"> <li>• 91% of GPs agreed</li> <li>• 74% of paediatricians agreed</li> </ul>	<ul style="list-style-type: none"> <li>• 80% of GPs agreed</li> <li>• 75% of paediatricians agreed</li> </ul>

<b>Percentage of respondent who have seen or heard about the HeadSmart campaign</b>	N/A	<ul style="list-style-type: none"> <li>• 59% of all respondents had become aware of the HeadSmart campaign</li> <li>• Stratified analysis showed that the awareness is lower in GP 26% than in paediatricians 73%.</li> </ul>
<b>Though which channel(s) the respondents came across HeadSmart</b>	N/A	<ul style="list-style-type: none"> <li>• Colleges or professional bodies 62%;</li> <li>• Posters or information packs at workplace 25%;</li> <li>• National or regional meetings 24%;</li> <li>• Personal discussion with colleague 21%</li> <li>• Training sessions 19 %</li> </ul>
<b>Whether respondents have seen or used the HeadSmart materials</b>	N/A	<ul style="list-style-type: none"> <li>• 37% of have seen the symptom card.</li> <li>• 31% have seen the quick reference guide</li> <li>• 30% have seen the leaflet.</li> <li>• 19% have seen or visited HeadSmart website</li> </ul>
<b>How useful do respondents think the materials are/will be for healthcare professionals?</b>	N/A	<p>Percentage of respondents answered useful or extremely useful:</p> <ul style="list-style-type: none"> <li>• Quick reference guide 91%</li> <li>• HeadSmart website 82%</li> <li>• Leaflet 78%</li> <li>• Symptom card 74%,</li> <li>• Full clinical guideline 72%</li> <li>• Poster 66%</li> </ul>

## Summary

### Average length of symptom interval experienced by patients

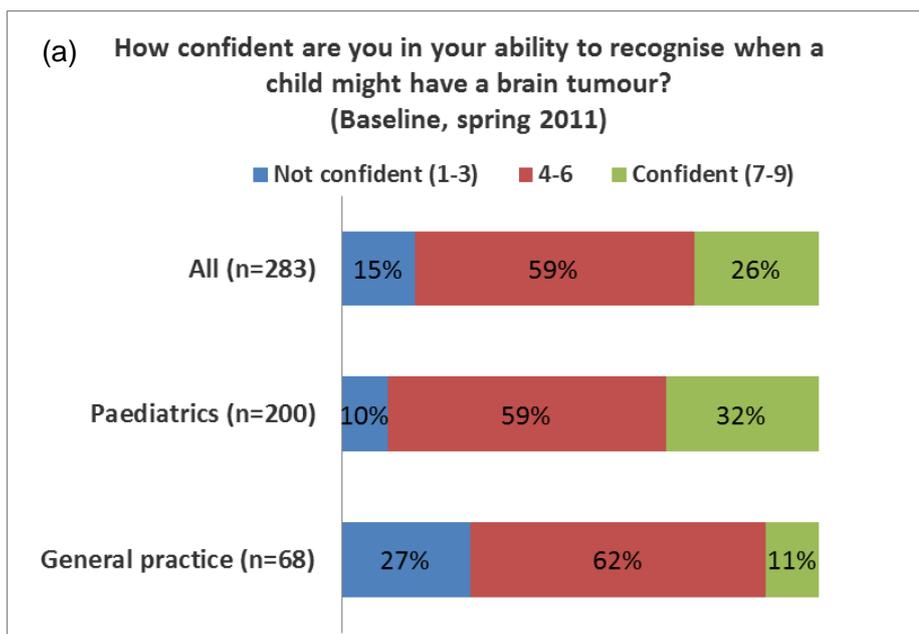
In the baseline survey, approximately 46% of healthcare professional respondents thought it took 3-4 months to diagnose a brain tumour (Figure 8). We seek to change this perception to 1 month and will measure this again in 12-months' time.

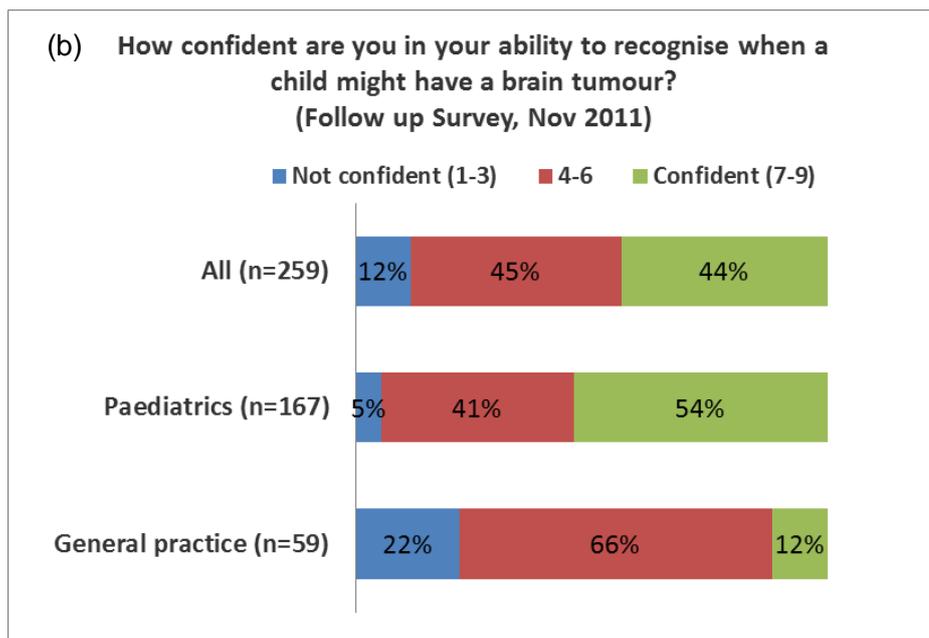


**Figure 8:** Healthcare professionals' perception of average length of symptom interval experienced by children diagnosed with brain tumour in England.

### Confidence in recognising brain tumour symptoms

Comparison of baseline survey and follow up survey responses showed that GPs (baseline 11% / follow up 12%) are less confident than paediatricians in recognising brain tumour cases (baseline 32% / follow up 54%) (Figure 9 (a) & (b)).





**Figure 9:** Confidence in ability of recognising brain tumour symptoms. Respondents were asked to scale their confidence of recognising a brain tumour case from 1= very unconfident to 9= very confident. (a): baseline survey; (b): follow up survey.

### Awareness of HeadSmart campaign and materials

	General Practice (n=61)		Paediatrics (n=192)		All respondents (n=289)	
	n	%	n	%	n	%
HeadSmart symptom card	9	15%	87	45%	106	37%
Quick reference guide	10	16%	69	36%	89	31%
HeadSmart leaflet	8	13%	70	36%	87	30%
HeadSmart website	8	13%	41	21%	55	19%
HeadSmart poster	4	7%	39	20%	53	18%
Full clinical guideline	2	3%	27	14%	35	12%

**Figure 10:** Number and percentage of follow up survey participants who have seen or used the HeadSmart campaign materials.

Six months after the campaign launch, about 60% of the follow up survey respondents are aware of the HeadSmart campaign; and over 30% of all respondents have seen or used our symptom card, quick reference guide and leaflets (Figure 10). Colleges and professional bodies play an important role in distributing the messages however we noticed the awareness among GPs required further improvement.

We were also informed from the survey results that of all project materials, poster was probably less useful, which matched the experience of the Meningitis Campaign (discussion on training session, December 2011).

## Feedback received from healthcare professionals and public

"Thank you for such a valuable resource" **GP**

"The issue of children's brain tumours need increasing publicity to help drive down delays in diagnosis. Using HeadSmart will help!" **Paediatrician**

"A much needed campaign" **Parent**

"Main thing that would work I feel would be documentaries on these children...television seems the only way to reach a lot of people" **Member of public**

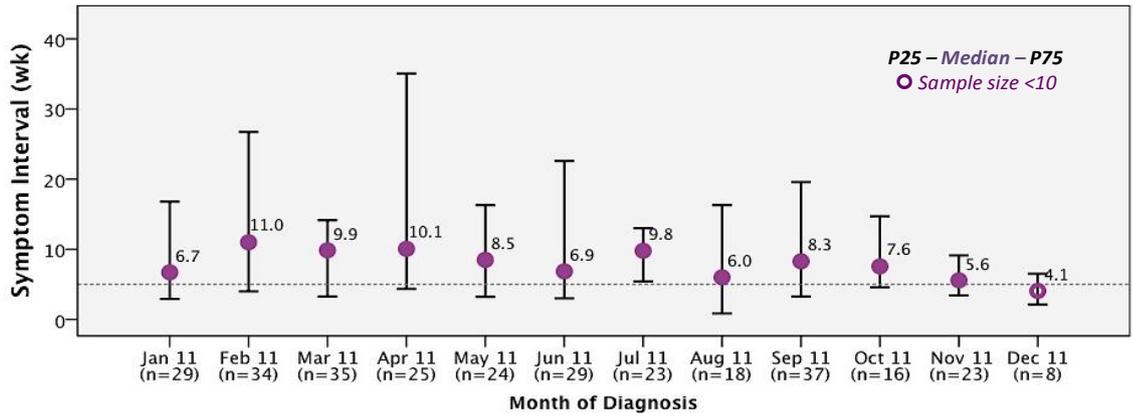
## Symptom Interval Data

Symptom interval details can be seen in Appendix 2 and Appendix 7.

**Table 4:** Symptom interval comparison - Pre HeadSmart project, pre- and post HeadSmart launch

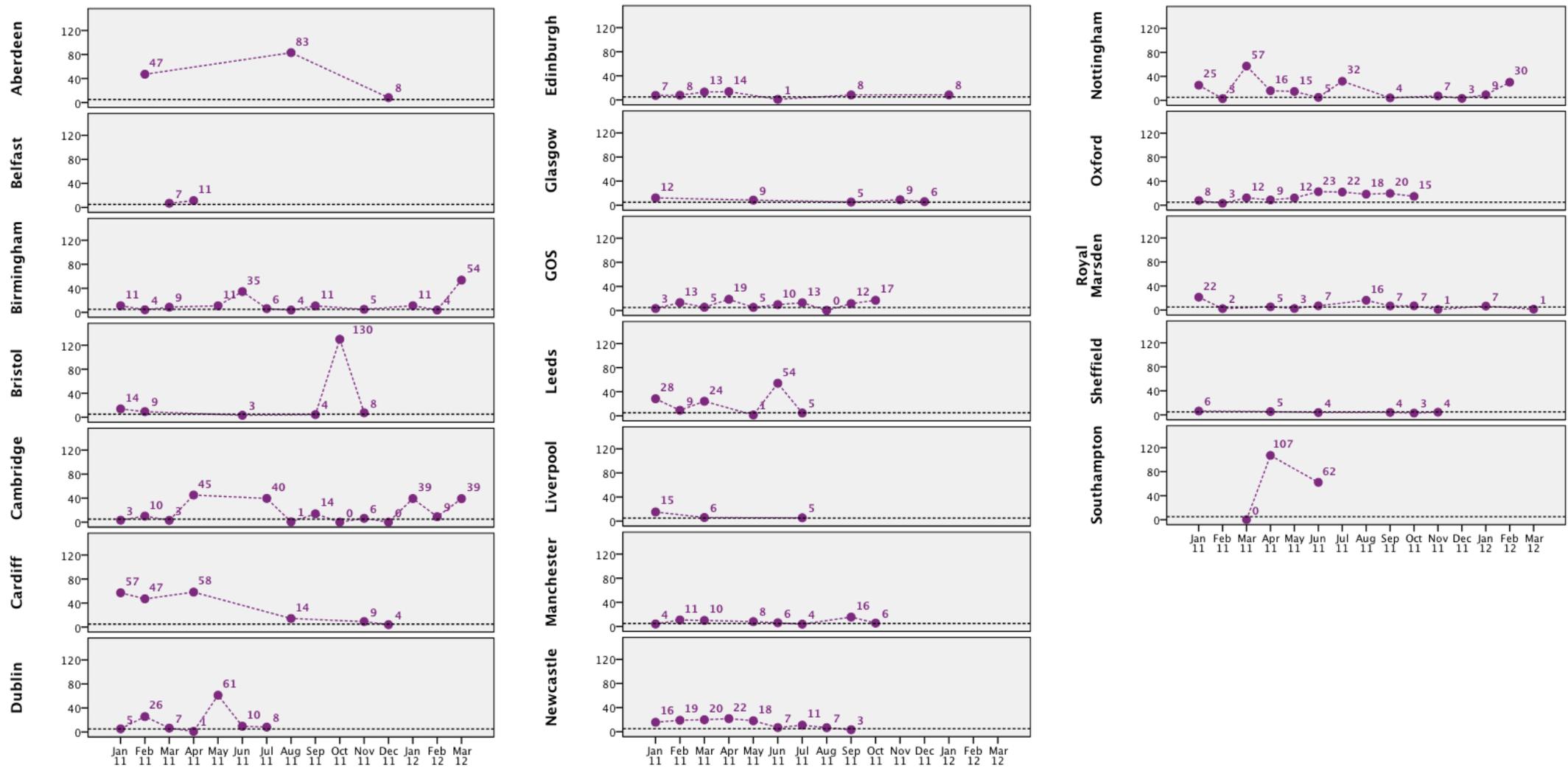
<b>Baseline SI in 2008</b>	<b>Pre launch Jan 2011 - May 2011</b>	<b>Post launch June 2011 – 15 March</b>
13.4 weeks	9.2 weeks	7.2 weeks
Wilne et al. reviewed medical notes and collected symptom interval of 139 patients diagnosed between 2004-2006 from four centres in England (Sheffield, Nottingham, Birmingham and Southampton). Median symptom interval is 3.3 months (14 weeks).	151 patients  Clinical champions submitted symptom interval data from January 2011	176 patients  Clinical Champions continued to submit symptom interval data.  Worth noting that data is submitted on a historical basis and therefore SI is monitored closely until data from all centres from each month is captured

From January 2011 to 15<sup>th</sup> March 2012 there have been **327** patients' SI details submitted by 19 CCLG neuro-oncology treatment centres. Among those 301 were diagnosed in 2011, representing an notable 70% of the predicted number of children with brain tumours in the UK.



**Figure 11:** Symptom interval of brain tumour cases diagnosed in 2011. Dotted line represents HeadSmart SI target (6 weeks). Purple circles represent median symptom interval of the month; high and low bars represent 75<sup>th</sup> percentile and 25<sup>th</sup> percentile, respectively. (Please note that only patients diagnosed in 2011 are presented in the figure (n=301), total numbers therefore do not add up to 327)

Individual centre performance is shown in the Figure 12 below. Clinical champions are all engaged and submitting symptom interval data. At this stage sample size was still too small when stratified by centre, and therefore the results should not be over-interpreted. Symptom interval, however, showed significance between - and within - centre variation. Data collection will continue in 2012 and we anticipate having sufficient numbers to conduct formal statistical analysis in the future.

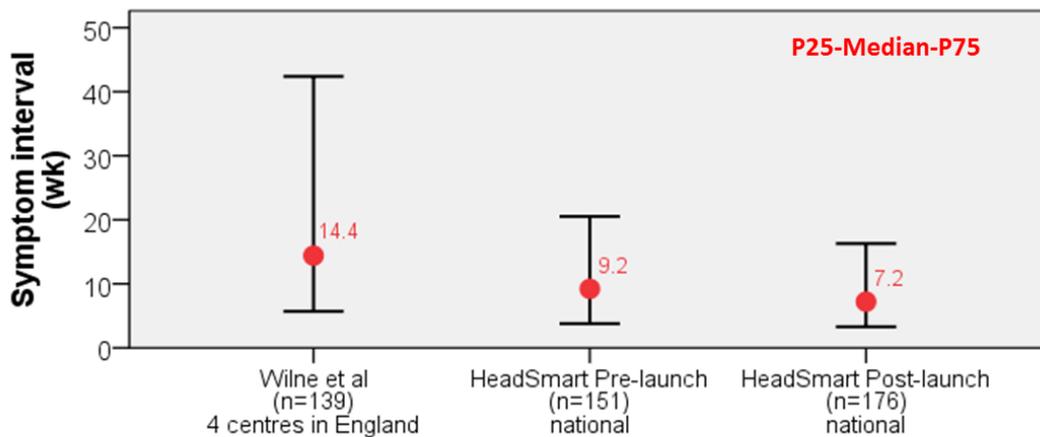


**Figure 12:** Symptom interval by month of diagnosis and centre. Purple circle represent median symptom interval in weeks and dotted line represent HeadSmart target

### Comparison with other UK studies

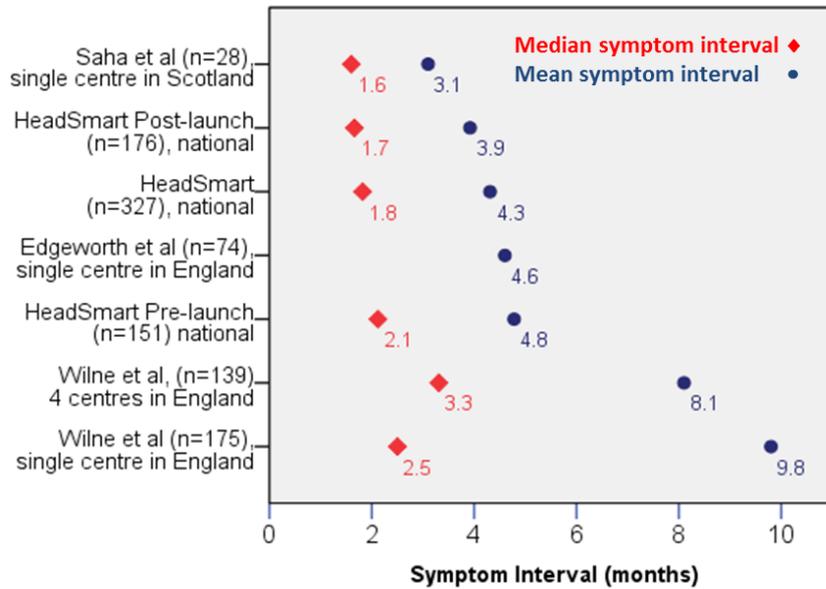
It is encouraging that compared with an earlier multi-centre study conducted by Dr Wilne (Fig 13), interquartile range seems to decrease, indicating less variation in SI, and the comparison among three time periods in two cohorts showed significant difference (Kruskal- Wallis test  $p < 0.01$ ). This difference between the two cohorts could be due to a number of reasons including improvements in access to CNS imaging, the location of the cohorts (*i.e.* the four centres Dr Wilne studied in 2004-2006 were all in England and HeadSmart covers UK and Republic of Ireland); or, a true improvement related to other factors.

The difference between pre and post launch was not statistically significant (Mann-Whitney U test,  $p = 0.094$ ). We expect symptom interval will decrease slowly but will reach significance level at some point if the impact of the campaign is further enhanced and assimilated into practice. Further, more verifiable, data collection is required to monitor long-term trend and determine statistical significance.



**Figure 13:** Comparison of median symptom interval (in weeks). Left to right: Pre-HeadSmart project (2004-2006) data published by Wilne et al, HeadSmart pre-launch (Jan –May 2-11) and HeadSmart post-launch (June 2011 – 15<sup>th</sup> March 2012).

We have also compared our SI data with other UK studies (Figure 14). Median SI of HeadSmart post-launch cohort is now very close to the best performer, which is a single centre study in Edinburgh (1.6 months). A significant change in data distribution has occurred with the mean moving closer to median, indicating significant reduction in the number of cases with very prolonged symptom intervals.



**Figure 14:** Symptom interval comparison – other UK studies & HeadSmart. Red diamonds and blue circles represent median and mean symptom interval, respectively.

### Referral pathways

Data on patients' referral pathways, in particular their place of care at the time of diagnostic imaging and the use of urgent cancer referral pathways, were also collected from the centres.

Overall, 38.5% of the patients were scanned as inpatient; 30% as outpatients; and 20% from the emergency department. Comparison of pre- and post-launch data showed that less post-launch patients had CNS scan under the care of outpatients (39.1% and 22.7% for pre and post launch, respectively). This could be an early sign of referral pathway changing to a prioritised emergency access; this needs to be explored further with Health Service data.

The use of the "two week wait" urgent cancer referral pathway remains very low - only 3% of children were referred via this route and there was no significant difference before and after HeadSmart launch.

**Table 5:** Patient's place of care at the time of CNS imaging ordered and usage of urgent cancer referral

	Total		Pre-launch		Post-launch	
	n	%	n	%	n	%
<b>Place of care when CNS imaging was ordered</b> ( $p=0.022$ )						
Inpatient	126	38.5%	54	35.8%	72	40.9%
Outpatient	99	30.3%	59	39.1%	40	22.7%
Emergency department	65	19.9%	23	15.2%	42	23.9%
Other	8	2.4%	2	1.3%	6	3.4%
Not known	29	8.9%	13	8.6%	16	9.1%
<b>Patient referred by a 2 week wait urgent cancer referral</b> ( $p=0.232$ )						
Yes	10	3.1%	3	2.0%	7	4.0%
No	251	76.8%	122	80.8%	129	73.3%
Don't know	66	20.2%	26	17.2%	40	22.7%

### Website and social media uses:

The HeadSmart website has had over 19,000 hits since it launched in June 2011 (8-15 June 2011, 7866 hits; 16 June 2011 – 29 March 2012, 11,514). The HeadSmart Facebook page has around 700 'likes' with regular postings and 'sharings' and the recently launched Twitter feed already has nearly 100 followers.

### Balancing Measures:

Throughout this campaign there have been two relevant concerns raised. The first is that raising awareness of childhood brain tumours will lead to unnecessary anxiety in parents, carers and young people and the second is that, as a result of raising awareness, primary and secondary care and diagnostic imaging will see a large increase in the number of children referred for consideration of a brain tumour who do not in fact have a tumour.

There is not very widespread public awareness of the campaign as yet so we are unable to comment on its impact on anxiety and presentation to primary care. Small sample surveys, however, suggest that parents and carers find the information useful and 66% of respondents (39 out of 59) said they would feel more confident discussing their concerns with a doctor if they had an information card with them during the consultation.

As a marker of referral to secondary care and diagnostic imaging we are studying the number of referrals to the East Midlands children's cancer primary treatment centre for central nervous system imaging to confirm or exclude a brain tumour. Analysis is on-going; however early results do not suggest a significant increase in imaging referrals.

The reduction in symptom interval and symptom interval variation (Figure 13) will in part be due to factors other than the HeadSmart campaign (demonstrated by the fact the SI has reduced prior to campaign launch). There has been increasing awareness throughout the healthcare profession of potential signs and symptoms of cancer driven in part by the Department of Health National Awareness and Early Diagnosis Initiative. Whilst this has been predominantly directed at adult cancer diagnosis it may have also had an effect on the identification of brain tumours in children.

## **Website Usage Outcome Measures**

On the launch week in June 2011, the HeadSmart website had **7866** website hits. (Refer to Appendix 10)

- Total of over 19,000 hits (16 June 2011 – 29 March 2012)
- Overall around 75% are new visitors and 25 % are returning visitors
- Visits mainly from the UK, USA and New Zealand (See Appendix 10c)
- Homepage, campaign materials and personal stories are most popular pages
- 45% were through search engines, 34 % through referral traffic
- The website has a contact form, for people with questions or who want to get involved, and on average we have about 10 responses a week via this route, which again highlights that the website is being well-used.

An additional component to the website, an education module for health professionals has been launched in March 2012, towards the end of the project. Although it is too early to report usage figures, we have received quantitative and qualitative feedback about the module from testing with health professionals. The testing also showed that health professional's confidence in their ability to recognise when a child might have a brain tumour increased through doing the module from an average of 4.5 to 5.3 on a scale of 1 to 7. Of the respondents whose confidence at the start was 1 or 2 out of 7, 66% had a confidence of 6 after completing the module.

*"Having been introduced to the site for the first time today, looking around it's a fantastic resource. I have made it, and the survey, available to students and it will enhance not just the curriculum content but student's awareness, reflection and application of the evidence."*

### ***Paediatrician feedback on the website***

*"The website is informative, user-friendly and accessible easily to health professionals and parents alike"*

### ***Paediatrician feedback on website***

## **Health Economics Impact**

Working with health economists at NCC-WCH, we have defined the data required to populate the model, identified data required for the health economics model and developed a blank model. However data collection has been a challenge (see section 8.3).

We are currently at the second phase. We have identified sources of data in the process of publication which will assist with data collection and further drafting the model. This is on-going and we anticipate populating the model, interpreting the results and providing a brief report summarising the results of the health economics model and the key findings by June 2012.

## **Healthcare policy and strategy**

Part of the campaign implementation strategy has been to influence national healthcare policy. The standard of care for management of potential malignancy in primary care in the UK is currently provided by the NICE "Referral guidelines for suspected cancer". Incorporation of the evidence-based principles of the HeadSmart guidance into this document would further disseminate and support implementation. The NICE guidelines are currently undergoing review. Papers published as part of the HeadSmart project have been identified by NICE as important

clinical evidence that should be considered in the guideline review. One of the project team (SW) has participated in early scoping for the reviewed NICE guidance.

### **Presentation of the HeadSmart campaign at regional and national meetings**

One important method of dissemination among the healthcare profession is presentation of material at regional and national meetings and conferences. The HeadSmart campaign has been widely selected for presentation at professional meetings and has been presented at a wide variety of meetings and conferences (See Appendices).

### **Publication of information about HeadSmart in public and professional literature**

A further important dissemination method is the publication of articles about HeadSmart in the healthcare professional and public literature and press. Since the project start, a significant number of articles have been published including the following:

**Table 6:** List of media links created by public launch

<b>Date</b>	<b>Media/title</b>	<b>Link</b>
8 June 2011	ITN	<a href="http://www.itv.com/news/child-tumour-signs68731/">http://www.itv.com/news/child-tumour-signs68731/</a>
8 June 2011	BBC5 Live	<a href="http://www.bbc.co.uk/programmes/b011p0yb">http://www.bbc.co.uk/programmes/b011p0yb</a> Click on listen now from <a href="#">this link</a> and scroll the bar along to 1.41.37 to hear Harry's story.
8 June 2011	BBC Radio 4 – Today	<a href="http://news.bbc.co.uk/today/hi/today/newsid_950700/0/9507607.stm">http://news.bbc.co.uk/today/hi/today/newsid_950700/0/9507607.stm</a>
8 June 2011	Eagle FM	Link off air
8 June 2011	Sky News	<a href="http://news.sky.com/home/uk-news/article/16007598">http://news.sky.com/home/uk-news/article/16007598</a>
8 June 2011	BBC News Online	<a href="http://www.bbc.co.uk/news/health-13685412">http://www.bbc.co.uk/news/health-13685412</a>
20 November 2011	Daily Star – OK! Extra magazine: Take 5: Real Life	<a href="http://braintumourtrust.co.uk/wp/wp-content/uploads/2011/11/Star-and-Mirror-magazine-articles-Sunday-20-Nov-2011-2.pdf">http://braintumourtrust.co.uk/wp/wp-content/uploads/2011/11/Star-and-Mirror-magazine-articles-Sunday-20-Nov-2011-2.pdf</a>
5 January 2012	Staffordshire Newsletter, Getting smarter over tumour symptoms	<a href="http://www.staffordshirenewsletter.co.uk/News/Letters/Getting-smarter-over-tumour-symptoms-05012012.htm">http://www.staffordshirenewsletter.co.uk/News/Letters/Getting-smarter-over-tumour-symptoms-05012012.htm</a>
27 February 2012	BBC South Today	<a href="http://www.youtube.com/watch?v=ZPqC-ZRrgYM">http://www.youtube.com/watch?v=ZPqC-ZRrgYM</a>
18 March 2012	You magazine, Daily Mail “Our courage kept us strong”	<a href="http://www.dailymail.co.uk/home/you/article-2114469/Our-shared-courage-keeps-strong.html">http://www.dailymail.co.uk/home/you/article-2114469/Our-shared-courage-keeps-strong.html</a>

## Quality of Care Received by Patients

The HeadSmart launch on 8<sup>th</sup> June proved to be hugely successful; the Department of Health keynote speaker stated *"I was delighted to attend the HeadSmart launch, as I am very keen to see an improvement in earlier diagnosis of cancers in children and young people....I wish the HeadSmart campaign every success."* **Dr Sheila Shribman, CBE, National Clinical Director for Children, Young People and Maternity Services**

In addition there has been:

1. Recognition of the HeadSmart campaign in healthcare policy and strategy
2. Presentation of the HeadSmart campaign at national and international meetings
3. Publication of information about HeadSmart in public and professional literature

Currently, it is difficult to assess whether the campaign has made any significant improvement in the quality of care that patients receive, due to the relatively low numbers of new cases being diagnosed since the launch (297 cases). The quote below demonstrates the quality of care that one patient received by using the shared decision-making website.

*"I saw a patient on 24th June 2011, who had been having problems with headaches for many months. Her mother had seen one of the HeadSmart cards at the GPs and had checked the website. She was worried that her daughter might have a tumour...We went through the website and by looking at all the other criteria and being able to demonstrate that she had grown normally again between March and June, she was much more reassured that her daughter did not have a tumour. We did decide to do a scan anyway (as her underlying medical condition could predispose her to CSF flow disruption) and this was normal."*

**Consultant Paediatrician, Service Lead Paediatric Medicine**

### **3.2 Please provide an assessment of the quality and robustness of the data that you have used, including comment on the validity and reliability of your measures, both qualitative and quantitative.**

The HeadSmart project aims to reduce the median symptom interval for childhood brain tumours to 5 weeks by enhancing the awareness in both the public and healthcare professionals of the signs and symptoms that can occur in childhood brain tumours and how these should be investigated. Previous UK studies in this subject were either single centres or centres in England only. Using the same definition and similar methods to Wilne et al., the HeadSmart cohort has one of the biggest collections of symptom interval data – on 15<sup>th</sup> March we have received data of 327 patients from 19 centres.

Similar to the Office for National Statistics (ONS) Opinions survey, the GfK NOP Omnibus survey population was designed to be representative of adults over the age of 16 in the UK. Stratified random probability sampling was used to select potential participants from the postcode address file for each survey. Self-selection on the basis of subject area can therefore be avoided. The questionnaire was reviewed by senior clinicians and marketing survey advisors and was approved by the project board. The professional awareness questionnaire survey link was distributed via Colleges, formal and informal email networks. Invitations to complete the survey were sent to paediatricians, general practitioners and emergency department doctors.

There were however some barriers to data collection and limitations to the data collected, these are summarised below in Tables 7-9:

**Table 7:** Barriers and limitations of data collection – symptom interval

<b>Symptom Interval</b>	
<b>What were the barriers or difficulties you encountered in obtaining good quality data?</b>	<p><b>Competing priority</b> Collection of symptom interval data from the CCLG centres was not mandatory and therefore centres provided varying amounts of data and within a variable time frame. There was no funding support for data collection and therefore we were reliant upon each centre providing data as a “good will” gesture.</p> <p><b>Missing data – patients not registered</b> * Patients from whom we have no data may have different characteristics or diagnostic pathways.</p> <p><b>Recall error and recall bias</b> HeadSmart used similar methodology to previous studies so the results would be comparable. Recall error is inevitable and we assume it was random and non-deferential. We acknowledge the risk of recall bias when collecting symptom onset date from medical notes or patient/family recall. Our intention is to monitor changes and trends over time, not to measure the impact of recall bias. However, we have encouraged clinical champions to submit data contemporaneously.</p>
<b>What assumptions have been made?</b>	<p>All centres were asked to submitted 3 key dates: date of first symptom onset, date first presentation to healthcare and date of diagnosis, so we are able to do calculations of interval of any two dates ourselves.</p> <p>We assume that all key dates submitted for symptom interval calculation were on or close to the actual event date; and any errors were random and non-differential.</p>
<b>What limitations are there in your analysis?</b>	<p>The main limitation in our analysis is inevitably, small sample size. A third of the treatment centres registered fewer than 20 patients per year, which made it difficult to plot centre performance by month of diagnosis. Further data collection would be extremely valuable for follow up and also for more detailed analysis, e.g., by tumour histology or tumour location.</p>

**Table 8:** Barriers and limitations of data collection – public awareness

<b>Public Awareness</b>	
<b>What were the barriers or difficulties you encountered in obtaining good quality data?</b>	<p><b>Response rate</b> Response rate was 59% (647 out of 1105) and 56% (648 out of 1154) in baseline and follow up surveys, respectively.</p> <p>This is similar to 61% from a previous publication using the Office for National Statistics (ONS) Opinions survey (Waller et al., 2009).</p>

<b>Public Awareness</b>	
<b>What assumptions have been made?</b>	We assume that there is no significant difference in brain tumour symptom awareness or behaviour in seeking medical advice and between respondents and non-respondents.
<b>What limitations are there in your analysis?</b>	A follow up survey was conducted 3 months after the HeadSmart launch to capture early impact. Repeat measurements at 12 months and 24 months after launch would be more useful in evaluating long-term outcome. These are planned.

**Table 9:** Barriers and limitations of data collection – professional awareness

<b>Professional Awareness</b>	
<b>What were the barriers or difficulties you encountered in obtaining good quality data?</b>	<b>Survey respondents</b> In the baseline survey GPs were invited via RCGP network, whilst in the follow up survey, GPs were invited via Macmillan GP network as RCGP were not able to help. Macmillan GPs have special interests in cancer support and might have better knowledge in this field.
<b>What assumptions have been made?</b>	We assume that there is no significant difference between respondents and non-respondents.
<b>What limitations are there in your analysis?</b>	Survey respondents were mainly paediatricians with a smaller number of GPs. We intend to repeat follow up surveys at 12 months and 24 months after launch, and expand the survey to other clinical and allied healthcare professionals involved in the diagnostic pathways.

### 3.3 What impact has this project had?

Please refer back to abstract on page 2.

- We have raised awareness of brain tumours (see survey results appendix 5 and 6) and we have also raised awareness of the HeadSmart website and clinicians are beginning to use this.
- Materials have been distributed across the UK in a breadth of settings (Table 10)
- Recent discussions in the European Parliament have led to plans to roll HeadSmart out across the EU. This supports recommendations in the "Consultation on the UK Plan for Rare Diseases"..... 'In Europe, over 90% of all respondents were supportive of more European collaboration on rare diseases'.

- We have secured good relationships with numerous public sector and social care organisations and worked across boundaries.
- Early data suggests that **the symptom interval experienced by children newly diagnosed with a brain tumour is reducing** – further data collection is necessary to determine whether this reduction is sustained and significant.
- Clinicians now have access to a decision support website and parents and carers have easy access to information on the website.

*"I just thought I would let you know that I have just seen two new patients in clinic with headache and followed the HeadSmart guidance (one reassure – one review). It was really easy to follow and I suspect that will not lead to a huge increase in referrals of non-worrying children but pick up the ones you want. Congratulations on an excellent resource!!!"*

***Paediatrician in Nottingham***

- We have developed our quality improvement skills. This has highlighted the importance of using multiple methods to achieve a single aim and the role dialogue and project ownership has in supporting practice change.
- We are contributing to the revision of the NICE "Referral guidelines for suspected cancer".

**Table 10:** HeadSmart Materials Dissemination (June 2011 – March 2012)

	<b>Business</b>	<b>Conferences/ Seminars</b>	<b>GP Surgery (direct)</b>	<b>Health Organisation (e.g. hospitals, Royal College members)</b>	<b>Private (these may then be distributed to schools, GP surgeries, hospitals etc)</b>	<b>Schools (inc pre-sch, nursery, primary, secondary, college, HE)</b>	<b>Umbrella Groups/ Charities</b>	<b>Direct Mailout to GP surgeries in E. Midlands for launch</b>
<b>Symptom card (92,352)</b>	680	5,580	2,104	21,323	16,271	1,964	4,650	39,780
<b>Posters (8,976)</b>	41	549	54	1,081	828	63	900	5,460
<b>Leaflets (9,899)</b>	150	640	178	2,735	1,240	305	751	3,900

### **Who has benefited and how?**

- A quarter of all childhood cancers occur in the brain. Brain tumours kill more children every year than any other cancer including leukaemia. It is these children and their families who have and who will benefit most from this project.
- The project team has gained experience in quality improvement methodology (PDSA'S, Driver Diagrams, Learning Sets and Social Movements) this leaves a positive lasting legacy with each of the partner organisations.
- The CCLG children's cancer network has gained experience in service improvement project
- The project has developed a model for successful collaboration between professional bodies, academia and the charitable sector.
- The initial symptoms of brain tumours often mimic those of more common and less serious childhood conditions and illnesses. The HeadSmart website and supporting materials highlight the particular symptoms and signs and presentation patterns that may indicate a brain tumour. Diagnosing a brain tumour requires brain imaging (preferably an MRI scan): the HeadSmart website provides advice as to when children and young people (and their families and carers) with symptoms and signs that may occur with a brain tumour should be reassured, reviewed / referred or scanned. GPs may only see one case of a brain tumour in a child in their entire career, this project gives direct guidance therefore directly beneficial to GPs as well as their patients.
- Patients and families who have experienced a prolonged symptom interval are pleased that attempts are being made to reduce this for future children diagnosed with a brain tumour.

*"Can't wait to see this campaign launched- it will make a massive impact" **family member***

- Increased awareness of all partner organisations

### **How has the intervention contributed to building clinical teams' skills in quality improvement?**

- The early training of the project team in QI methodology has focused our attention on easily measureable indicators as a way of designing and sustaining interventions to change clinical practice.
- The engagement with the clinical champions in collecting the key data has achieved buy-in by them for this national project which will help with its sustainability.
- Signs of early improvement in symptom interval from the November survey have identified the potential for QI methodology to improve service delivery.

### **How has it contributed to knowledge about how to engage clinicians in QI?**

- The application of QI methodology within the context of a project of this nature is of interest as it delivers an easily measureable series of interventions to accept or reject their efficacy.

- The collaboration between the three project stakeholders has been highly successful and has served to stimulate a review of practices in each of the organisations in the area of research in clinical guidance development.
- The project data is the focus of professional discussion surrounding the needs for health systems to be sensitive to the needs of children with rare and complex conditions and provides a model for streamlining their access to healthcare as a focus for service development. Recent work in the field of diabetes is similarly focussing on the symptom interval as a measure for quality care.
- This project has promoted professional debate between paediatrics and primary care regarding presentation of symptomatic disease to General Practitioners which are relatively common diseases in childhood.

#### **Any other benefits that have emerged that go beyond original scope of project**

- The diagnosis of brain tumours in children guideline has been accredited by NHS evidence.
- A pan-European campaign has been launched at the European Parliament. HeadSmart will be disseminated throughout the EU.

*"We found that the Children's Brain Tumour Research Centre demonstrated strong rigour of development in producing the Diagnosis of Brain Tumours in Children guideline. The recommendations are clear, unambiguous and easily identifiable. The quick reference and summary versions of the guideline are especially clear. Congratulations on achieving this excellent standard of guideline development."* **Chair of the NHS Evidence Advisory Committee, David Haslam**

- HeadSmart materials and resources are being distributed widely throughout the English speaking world: materials are being downloaded and website accessed (at no additional costs to the project) from clinicians and activists in Australia, New Zealand, the US and Canada for example.
- The HeadSmart project received written confirmation of support from Royal College of General Practitioners, the Association of Paediatric Emergency Medicine and the Children's Cancer and Leukaemia Group (CCLG).
- Significant progress was made by gaining accreditation on the guideline with the Royal College of Radiologists and the College of Emergency Medicine confirming this in June and July 2011.
- Public awareness is raised about the symptoms of brain tumours and there is enhanced understanding of how the public view neurological signs and symptoms and select different ways of obtaining relevant healthcare advice.
- Educational module has generic education value, applicable to both undergraduates and post-graduates, in offering training in neuro-diagnostics in childhood and functional neuro-anatomy skills.
- Parents of children diagnosed with a brain tumour who have seen or got involved in the HeadSmart campaign have reported to us that this has given them hope for other children and families, that it has given them something to focus on (particularly if they lost their child). It has given friends and family a way to join together to do something positive.

*"Do you know, it [being involved in HeadSmart] makes me feel better? I hadn't been feeling very well, anxiety attacks brought on by the fact that my son was now, four years later actually stable. [...] So, doing something positive, trying to get children there earlier so they can be much more successfully treated and saved and not have to suffer as much as my child has had to – well, it is about the only thing that makes sense in my life at the moment."* **Mother of a child with a brain tumour**

- Raised political awareness of brain tumours and delays in diagnosis.

*"I welcome the HeadSmart campaign. Our report 'Improving outcomes: a strategy for cancer' (published in January 2011) showed our commitment to raising awareness of less common cancers. The HeadSmart initiative fits well with this aim. I look forward to seeing the results of the campaign."* **Paul Burstow MP, Minister of State for the Department of Health**

### **Disadvantages**

- A small minority do not support the campaign, one GP said, *"In General Practice, about 1/3 of our consultations are to do with headaches and over 99% of these have a benign cause. I am worried that this campaign is going to feed into people's cancer phobia about what are, fortunately, very rare conditions."* However, the majority of responses are very positive and supportive of the campaign.
- The NICE Referral Guideline for Suspected Cancer has not been updated yet although we understand this is in the pipeline. We are hoping the Diagnosis of Brain Tumours in Children will be used to inform the update of the relevant section and we will monitor this going forwards. (Refer to page 5 please) NICE Guidelines are used by GPs and promoted by RCGPs as the 'Gold Standard' it is therefore hard to encourage using our guidelines as RCGP do not want to send out a mixed message.

In conclusion, if the early evidence of reduced symptom interval is subsequently verified, we hope that patients will have benefitted by enhanced pathway of referral, reduced risk of visual impairment, neurological injury and early death. It is too soon, however, to make these claims.

## **4. Discussion/ learning**

### **4.1 Summary**

Most important successes are:

- launching the campaign with its website with extensive broadcast coverage
- achieving awareness of HeadSmart within 4 months in 11% of the population
- establishing a method of collecting robust symptom interval data from every UK neuro oncology centre.
- measuring an early trend of reducing symptom interval data motivating clinicians to devote time to contribute to raising awareness.
- harnessing the expertise of the stakeholders organisations to host the project (RCPCH) and act together in publicity and strategy
- recruiting experts in PR/media and website design
- selecting excellent design scheme for materials and website

- linking the website with high quality NHS information sites,
- designing the website to accommodate training tools, videos, hyperlinks and feedback techniques to keep the website relevant
- establishing a network of clinical champions to act as monitors of symptom interval across the UK and Ireland
- establishing and promoting strong clinical leadership of HeadSmart, through five senior clinicians as membership of the Board
- collaborating with the Children's Cancer & Leukaemia Group (CCLG) CNS Tumour Special Interest Group and their leader, Dr Steve Lewis to select clinical champions across the whole of the UK to collect clinical data and disseminate materials and share the project's aims.
- linking to the Royal College of General Practitioners, (Dr Maureen Baker – Board Representative) to keep abreast of RCGP priorities for NHS Evidence and NICE approval as critical factors for guideline acceptance
- applying successfully for NHS Evidence accreditation
- engaging with NICE cancer referral guideline review
- planning sustainability through on-going engagement with the community champions in 2012 to assist with active dissemination across the regions
- identifying HeadSmart principles to link to the two-week wait referral monitoring, adverse outcome reporting within the National Patient Safety Agency and cancer registration by National Cancer Intelligence Network as priorities for shared policy for future health service monitoring beyond the life of this project

The difficulties encountered have been overcome by strong leadership by the Board Chair, supported by the Board members and amplified by the able management of the RCPCH, keeping the child's needs as the number one priority.

The area of difficulty lay in the Health Economic component; initially we had anticipated performing a systematic literature review. However, the scarcity of literature and the high anticipated cost made us decide to work with National Collaborative Centre for Women and Children's Health and start the process of health economic model design. This process was slowed by the scarcity of relevant data about existing pathways. Whilst we did have some audit data on referral pathways and also data on imaging usage, we were constrained in our model development by the lack of prospective data collection in primary care. Two projects working on GP Research Databases offered to fill this gap, however the process of analysis and publication has meant that this data is not available within the project time period. We anticipate its availability in April and expect this aspect of the project to be concluded by June 2012

#### **4.2 Please explain how you established the clinical community; how you think it impacted on the success of your project; what was the added value of approaching the problem through a clinical community?**

We established a national clinical community of Paediatric Oncologists through attending pre-organised Special Interest Groups (SIG) for Paediatric Oncologists using our clinical leadership to initiate and sustain collaborative relationships.

All 22 neuro-oncology centres are represented at this meeting and therefore it was the most appropriate way to engage and encourage them to work together with us. With our QI Adviser we were able to explain the QI methodology and inspire them to get involved data collection, creating a social movement.

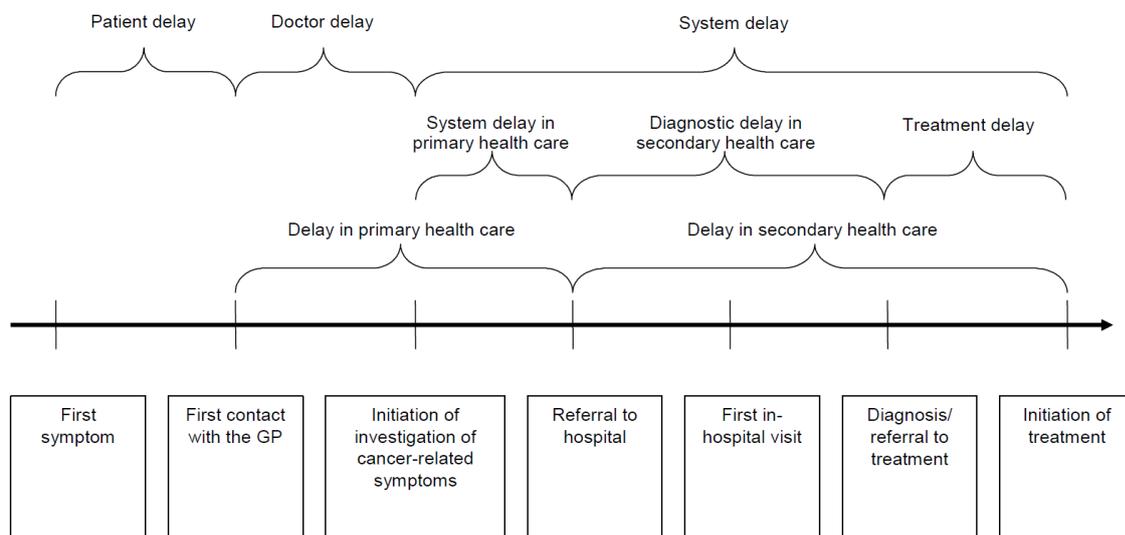
- The Clinical Champions signed up to submitting data on new patients from January 2011 and agreed to try and raise awareness and influence other healthcare professionals.
- The HeadSmart team have regular slots at the quarterly SIG meetings and this enabled us to feedback data to the group and have informal discussions on results.
- A Huddle page was created to enable the champions to communicate as a group, share ideas, discuss problems and keep up to date with project news. Furthermore, it provided a valuable central place to store documents meaning everyone was using the same materials, ensuring consistency.
- By working with our champions we have been successful at obtaining symptom interval data, which is a key achievement.
- We have managed to spread our message widely across the UK through well respected clinicians who are able to promote the campaign and materials.

**4.3 Please tell us about your achievements, the challenges and the things that didn't work out quite as you planned.**

**What did we set out to achieve?**

We set out to convert the Symptom Interval (SI) from **3 into 1** month across the UK by raising public and professional awareness of brain tumour risk and symptomatology in the belief that this will change the culture of referral from:

- Step1: the initial awareness of concern for the patient and family, through to
- Step 2: seeking medical advice to select either reassurance, review or referral strategies, through to
- Step 3: feeding back to the patient and family the report of a brain scan, ordered as a result of this guided concern.



**Figure 15:** Categorisation of delay

We intended that, where symptoms were not indicative of brain tumour and a review or scan was not needed, **early reassurance**, would be offered. Where **review** was recommended the practitioner would become aware that their duty was to ensure that the review took place at the recommended time or sooner if needed. Where **referral** was required, the pathway to scan was associated with recommended time periods. Where a brain tumour was not diagnosed then the **reassurance** would permit alternative strategies to manage symptoms to proceed, knowing that this serious cause had been appropriately excluded. All these pieces of advice had been developed by the guideline development methodology, which had been accredited against standards of **NHS Evidence**.

### **Who was influencing whom?**

This purpose of this project was defined by those directly involved in the care of patients after diagnosis had been made (tertiary care) with the intention of influencing the actions of health care systems involved in diagnosis and care before diagnosis (primary and secondary care). This ambition of one sub group to change the behaviour of another sub group's behaviour with patients within the health system was the major challenge. Its success depended upon the **public and health professionals being engaged to act together in the interests of this patient group**, who are a minority, by virtue of their status as children (<25% of population), the specific symptomatology, which can mimic other more common conditions and the rarity of the disease presentations as well as the relative infrequency of the diagnosis as it occurs in only 500 cases per year in UK. The justification to act in this way was driven by the **public concern**, the **existing priority of early cancer diagnosis**, the prospect of improved outcomes and enhanced confidence and the **opportunity to save lives and reduce disability**. At the outset we greatly encouraged by the positive responses from a wide range of relevant Royal Colleges and professional organisations including:

- Royal College of General Practitioners
- Association of Paediatric Emergency Medicine
- \*Children's Cancer and Leukaemia Group (CCLG)
- Royal College of Paediatrics and Child Health- in Scotland, Wales and Ireland and Guideline Development Groups
- Royal College of Radiologists
- College of Emergency Medicine

\* *"The (CCLG) executive are very keen to support this campaign and would be happy to show links to it from the public and members parts of the website. They would also be very pleased for CCLG to be included as an organization that endorsed the campaign in the future."*

***Martin English, Secretary of UK Children's Cancer and Leukaemia Group Executive, July 2011***

### **Did QI methodology work?**

Being acutely aware of all these factors prior to launching this Campaign made us realise that our campaign may produce no measurable effect at all, as the challenges may be too great to overcome.

The driver diagram (Table 4) clearly sets out the 5 tasks for the programme:

1. Develop measures for outcome
2. Activate and engage the neuro-oncology units

3. Develop awareness campaigns for GPs
4. Develop awareness campaigns for paediatricians
5. Activate the public.

These clearly defined priorities which governed the projects tasks and activities. Without being clear about these, the project would have been less successful.

The driver diagram however did not identify the major challenge of website development, PR strategy and planning, delivering a successful launch event, promoting integration with national policy and establishing a health economic programme. These tasks were extremely challenging as they involved working with external partners and required the project team to commit additional time to major pieces of work. These were essential parts of the project and consumed a considerable amount of time and resource for which there was inadequate provision.

The pre-allocation of resources, prior to the establishment of these driver priorities, coupled with unrealistic expectations of project team's contributions, undoubtedly constrained some options and created significant pressures for all members of the project team. These pressures resulted in phases when individuals were over burdened with tasks and extremely challenging deadlines.

The geographical dislocation of the collaborating project teams imposed inevitable communication challenges. The three collaborating partners had distinct organisational cultures and priorities and were aiming to influence the NHS with its separate and distinct culture.

Despite these challenges the QI drivers was instrumental in welding the project team to its tasks and acting effectively to deliver the project's aims and objectives including a sustainability plan which is now in the process of implementation. **Strong leadership qualities by all partners** was an essential component of this success. This was driven by the belief that this project could **alter these young patients' experience and relieve them and their families of the distress that had been reported and prioritised for action in the public consultation processes.**

[http://braintumourtrust.co.uk/wp/wp-](http://braintumourtrust.co.uk/wp/wp-content/uploads/2010/10/Manifesto_4_everyone_brain_tumour_final_v01_october_2010.pdf)

[content/uploads/2010/10/Manifesto\\_4\\_everyone\\_brain\\_tumour\\_final\\_v01\\_october\\_2010.pdf](http://braintumourtrust.co.uk/wp/wp-content/uploads/2010/10/Manifesto_4_everyone_brain_tumour_final_v01_october_2010.pdf)

### **What have we achieved?**

We have developed and implemented a process for measuring outcome – **Symptom Interval**, by activating and engaging with the **Clinical Champions** working in the **neuro-oncology units**. We have started to **engage GPs** in our awareness campaigns by attending their conferences and seeking their views through the website's development and to some degree through surveys. We have been supported by our **GP linkage on the Board (MB)** who advised that integrating our message through **NICE Cancer Referral Guidelines** was an essential step for **full RCGP engagement**. The RCGP however have enthusiastically engaged in developing an **e-learning module**, which will be complete and ready for dissemination in summer 2012. Despite these steps the surveys showed no evidence of change in confidence for making the diagnosis of brain tumour, amongst GPs.

In contrast we have successfully enhanced awareness for **paediatricians** through our close working links to the **RCPCH**. Surveys showed that paediatricians expected it to take 3-4 months to diagnose a brain tumour in childhood. After the launch over 60% are aware of HeadSmart campaign, 45% have seen or used a symptom card and confidence in making a diagnosis of brain tumour had risen from 32% - 54% and the proportion not confident, fell from 10% - 5%. We have set the target of one month for the future. Preliminary data indicates that the median and mean symptom intervals are falling.

We are in the process **of activating the public**, having achieved **11% awareness** of HeadSmart by October 2011, after the June launch. This was considered good progress. The **sustainability programme** involving **Community Champions** and a variety of marketing techniques provides a method for sustaining progress.

### **Dissemination**

The dissemination has had two broad audiences:

1. Health professionals, particularly GPs, paediatricians and emergency medicine professionals
2. Public, particularly parents, carers and grandparents, and others with caring responsibilities for children and young adults.

The principle of HeadSmart dissemination has been to encompass both a systematic methodology as well as organic to widen audiences.

**Medical press and journals.** The campaign has targeted medical press (both specialist and generalist) such as Pulse, BMJ, HSJ, GP, Medscape, Medical News Today, etc, on and offline.

**Conference speakers/stands.** Conferences have provided opportunities to communicate messages directly to target audiences, often in large numbers. We have been strategic in attendance and provision of materials, these include; Royal College of Radiologists - Annual Conference; College of Emergency Medicine - Annual Conference; British Association for Community Child Health - Annual Scientific Meeting; Royal College of GPs - Annual Conference; Community Practitioners and Health Visitors Association – Annual Professional Conference. (Appendix 22 - Table of Events)

**Clinical Champions.** Members of the project board and Clinical Champions have taken part in at least 13 peer-to-peer presentations, although others may have taken place of which we are unaware. We are seeking to widen this further through seeking champions outside of neuro-oncology. The project has produced a variety of decks of slides and toolkit for clinical champions to support dissemination. We have also published region by region comparative data on line and in e-news to drive performance in the collection of SI data.

**Celebrity Ambassadors** We have a number of celebrity ambassadors that have helped to raise the profile of the campaign in the public:

*"Brain Tumours are the leading cause of cancer deaths in children, and the UK is slower than other countries at spotting the signs. We need to change this and by providing practical resources to help parents, and doctors, HeadSmart will save and improve lives".*

**Dawn French**, SDBTT Patron

*"I'm supporting the HeadSmart campaign, which aims to raise awareness of brain tumour symptoms in children and young people, because I believe it is vital that we equip parents with the information they need to be brain tumour aware. 500 children each year are diagnosed with a brain tumour and this campaign aims to ensure that they are all diagnosed swiftly"*

**Hayley Mills**, SDBTT Patron

*"Someone very close to my family died in his mid-teens from a brain tumour. Had it been spotted sooner, he might still be with us and his wonderful family might have been spared all that agony. That is why, I am giving my full support to the HeadSmart Campaign."*

**Alistair Stewart**, SDBTT Patron

*Losing a member of my family to this dreadful disease is one of the many reasons I am giving my full support to the HeadSmart Campaign."*

**Johnny Wilkinson**, SDBTT Patron

**Charity Stakeholder Launch** took place on 13<sup>th</sup> July. Over 30 charities were invited with the aim of helping to promote the campaign. 'Terms of Engagement' for charities involvement with the project will be developed. A charity support event was held and numerous charities associated with brain tumours and cancer are supportive of the campaign. The Brain Tumour Consortium has discussed and highlighted the HeadSmart project in its work.

**Community champions.** SDBTT have distributed campaign materials to families that have offered to be the 'voice of the campaign' to help raise awareness in their local areas. SDBTT are progressing this over the following 18 months having secured external funding. A detailed Community Champions toolkit is now in production with this funding as well as media training for parents to enable them to further raise awareness locally.

**Campaign ambassadors.** A wide range of health and other professionals expressing an interest in the project is being developed and provided with information and materials to disseminate the campaign messages among their peers.

**Media.** The targets for the media work have included the following: Female press (Pick Me Up, Mumsnet – in June 2012); Male press (GQ in Autumn 2012); parenting press and general press – targeting local and national papers with relevant, location based stories; as well as third party partner media – for example, Headway news and other cancer charity publications.

**Schools awareness.** It was clear that to raise as much awareness in schools as possible, we will take a multi-faceted communications approach: targeting parents through schools e-communications tools; targeting teachers through relevant websites, magazines and journals and trade associations; targeting young people through VLEs.

**Young people.** Young people are notoriously difficult to get to take notice of corporate communications. To ensure best possible coverage, we have begun to target relevant youth-related media, seeking to identify and recruit a specific 'youth' celebrity ambassadors; engaged the major youth organisations to disseminate in later 2012 / 13.

#### **Which materials and methods worked best?**

The **printed materials** including the symptom card, quick reference guide, leaflet, poster and full guideline have been extensively disseminated (Table 10). The quick reference guide is the component with the largest print and distribution potential. The achievement of 45% awareness of it amongst paediatricians was clear evidence of effective distribution.

We successfully developed a high quality, **decision support website** with associated campaign and educational materials to raise awareness of brain tumour symptoms in children and young people. The website has undergone prolonged iterative development and was fully complete in its first phase at the end of March 2012. The latter phases of development included considerable professional and public feedback, upon which we have acted. The development of an educational module has

attracted particular interest from professionals and will support the RCGP training module, permitting a comprehensive programme to be delivered.

**HeadSmart education module** Test Your Learning

**SIGNS AND SYMPTOMS OF BRAIN TUMOURS** MENU

**Question** Exercise Instruction

The symptoms and signs caused by brain tumours are determined in part by the area of the brain affected. Assume each of the signs below is caused by a brain tumour and link the sign to the relevant area of the brain. Click on the 'Exercise Instruction' button for help on how to answer this question.

- Horizontal nystagmus (a)
- Vertical nystagmus (b)
- Bulbar palsy (c)
- Seventh (facial nerve) palsy (d)
- Delayed puberty (e)
- Reduced visual acuity (f)
- Severe growth faltering (diencephalic syndrome) (g)
- Seizures (h)
- Ataxia (i)

**Cerebellum** (c)

**Central Brain\*** (b)

**Brain Stem** (d)

**Cerebral Hemisphere** (a)

\* Central brain includes third ventricle, tectal plate, pineal gland, pituitary, thalamus, hypothalamus, optic pathway, basal ganglia

PRINT PREVIOUS REPLAY NEXT

**Figure 16:** Front page of interactive education module – launched March 2012  
<http://www.headsmart.org.uk>

**Postal mailshots.** A postal mailshot to GP surgeries in the East Midlands was undertaken in June 2011. A symptom card is being included in a mailing to all RCPCH members in autumn 2011. Beyond this, no further postal mailshots are planned at this stage. This has been an expensive method of communication, and would need additional funding if it was to be pursued. Its effectiveness for delivering the messages and achieving behaviour change would need to be further considered.

**Social media.** Since the launch of HeadSmart, the project has developed engaging, relevant content and promoted the HeadSmart social media pages to increase awareness and engagement.

The **policy strategy** was substantially rewarded by achieving NHS Evidence Accreditation. Our engagement with NICE Cancer Referral Guideline Review, and the HeadSmart evidence base publications being adopted by that review process, gives considerable hope that the HeadSmart principles will be incorporated in the next version of this document. This would then deliver the requirement for full RCGP endorsement and commitment. We are working the National Cancer Intelligence Network to influence the inclusion of Symptom Interval as a required data item for cancer registration.

Unexpectedly, considerable interest was shown in HeadSmart in the **European Parliament** as a result of MEP Glenis Willmott becoming involved in the HeadSmart launch in Nottingham, within her constituency. This MEP is co-chair of Health committee and hosted a series of meetings concerned with rare cancer, where the needs of children's cancers were debated and HeadSmart was featured.

A press release was issued on 15 February announcing an intention to develop similar initiatives across Europe. A meeting between parents' groups and national representatives of oncology groups from Austria, Germany, Spain, France, Sweden and Denmark have all expressed interest. A meeting will be held, hosted by International Confederation of Childhood Cancer Parent Organisations and the SIOP Brain Tumour Group at the forthcoming SIOP meeting in London in October 2012. Abstracts describing the HeadSmart Campaign have been submitted to national and international meetings concerned with paediatrics and brain tumours. An active programme of authored work for professional journals is being sustained.

The linkage with National Awareness and Early Diagnosis initiative, whilst of interest has not proved as successful a linkage as we had hoped. Whilst NAEDI clearly are interested in promoting early diagnosis of cancer of all types. Applications for research funds from HeadSmart and 5 other children and young people's projects linked to early cancer diagnosis were all rejected. This is a remaining challenge. We are exploring other avenues of academic funding. The link to Professor Michel Coleman at the London School of Hygiene and Tropical Medicine, through the Lead Clinician's co-supervision of a PhD student, focussing upon diagnosis of childhood brain tumours using GPRD HES and Cancer Registries datasets, places us in a strong position to explore the HeadSmart using this methodology in the years ahead. Furthermore, this source of data will prove invaluable in the proposed Health Economic evaluations that we intend to derive from the HeadSmart Health Economic project.

#### **What can we conclude at this time?**

HeadSmart - Be Brain Tumour Aware has been launched. The materials and methods have been well thought through and deemed acceptable to the profession and the public. There are policy developments occurring which will take HeadSmart's evidence base into account and reinforce its priority to respond to sustained public concern and to raise awareness for the profession. The preliminary evidence of enhanced awareness amongst the public and profession is highly motivating to those working in the sustainability programme. The ability to measure symptom interval real time will continue to focus the impact of awareness on the needs of the children.

We conclude with three thoughts:

1. Our aim is to reduce the SI from **3 into 1** month – we are already seeing significant progress in achieving this.
2. The professional expectation, currently, is that it takes 3-4 months to make the diagnosis. This is not acceptable to the project team.
3. To achieve our aim of **3 into 1** requires the profession to change their expectation in order to drive the service changes. This, alongside empowering parents from across the socio-economic spectrum, is the real challenge for the sustainability programme.

#### **4.4 Interpretation**

##### **Surveys not representative of our whole target audience**

In terms of professional awareness surveys, we had good responses from paediatric oncologists, but very few from other specialities. We were unable to reach our main target audience in the follow-up survey as RCGP were unable to help disseminate the survey to their users on our behalf. In future, it

would be worthwhile gaining commitment from a number of GP Clinical Champions for the project that could be points of contact and be advocates for the project.

It was challenging for us to disseminate the materials by post across the whole of the UK, because of logistics, funding, and our view that this was not the most efficient way of communicating our messages.

### **Disease incidence rates**

As outlined previously, the incidence rates of brain tumours in children are very low for the whole population. On average about 500 children a year are diagnosed with a brain tumour. If there is any change in symptom interval due to the project, we need to have enough data in order for it to be statistically valid.

### **Access to materials**

In the follow-up public awareness survey, 11% of people had heard of HeadSmart. There is a concern that some people would pay attention or pick up a symptom card only if they were already genuinely concerned about something serious. Early evidence is that parents are comfortable having a symptoms card in their medicine cabinet as they do with a meningitis symptoms card.

Finally, we felt that TV would be the best way of reaching a huge target audience across the country and across all socio-economic groups. We are currently in talk with production companies for documentaries on two main TV channels and we have been offered the opportunity of a distress space advert for Sky Family. Finally, HeadSmart materials are on-set for the next series of ITV's Monroe starring James Nesbitt.

## **5. Resources to share**

Attached in the appendices are the following documents:

- Survey Results and Charts (Appendices 5, 6, 7)
- HeadSmart Poster (Appendix 12)
- HeadSmart Leaflet (Appendix 13)
- HeadSmart Symptom Card (Appendix 14)
- HeadSmart Slideset - Healthcare Professionals (Appendix 15)
- Training materials from various workshops in 2011
- E-Newsletter & Newsletter to Clinical Champions
- QI learning

The quote below demonstrates that some members of the public have already found the materials useful:

*"A colleague of mine has just handed a flyer re HeadSmart to a friend of hers who's daughter has suddenly lost vision in one eye (half of her field of vision has gone black). With this knowledge her mum is going to take her straight to the GP and ask for a referral... this is just one instance of the HeadSmart message empowering parents to push for referrals."*

### **Nottingham**

## **6. Plans for Sustainability**

Sustaining a positive change within healthcare, resulting in a shorter symptom interval, which brings benefits to children and young people, is undoubtedly essential. Sustainability was taken into account throughout the project; determining actions for each of the resources, and ensuring that changes in government policy, for example, were monitored, being aware they could alter the shape of the project. A Sustainability Plan has been created, which can be seen in the appendices.

Our sustainability plans (available on request) include:

- Website training and future hosting, maintaining and developing
- Development of an e learning training tool to be disseminated across the RCGP's 40,000 membership in 2012 is a major factor for primary care engagement which will be monitored with respect to its impact.
- Maintaining clinical champion engagement
- Presentation of initial results at national and international, professional and public meetings
- Influencing policy through contact with the Department of Health and NICE
- Working with NCIN to support collection of symptom interval data
- Development of an RCGP e-learning module of brain tumour recognition
- Working with the RCPCH on 'Spotting the Sick Child' module to include information about brain tumour presentation.
- Communications and PR strategy
- Applying for further prestigious awards

### **What have been the challenges to sustaining the work? How have you overcome them?**

Sustaining the positive changes brought about by the HeadSmart project can be challenging, as the HeadSmart project is not just about raising awareness levels but promoting change in numerous organisations across the country, and has the complex task of changing human behaviour on a large scale.

*"I still have anxieties about the benefit / risk of displaying posters about extremely rare conditions"*  
**GP Macmillan Adviser**

However, we were able to reassure professionals with this view by clearly explaining that patients have the right to be informed about high quality, evidence based information and that the materials should help with shared decision making. We are seeking to reassure as well as select those for review as referral.

The HeadSmart team ethos was to 'Inform, Inspire and Sustain'. We have informed stakeholders by creating educational tools and materials, inspired with real life, emotive stories from parents and young people, and will continue to sustain this with the same passion and enthusiasm, further details on this will be outlined below and can be found in the Marketing Strategy (see appendices).

Best practice recommends that clinical guidelines should be reviewed and updated every three years, therefore our Guidelines will be updated in 2013. The associated campaign materials and website will have their content updated accordingly, to ensure consistency. Both CBTRC and SDBTT will continue to work together beyond the life of the project.

### **Who has helped to sustain the work as business as usual?**

Symptom interval data will continue to be collected beyond the life of the project; this is important due to the low incidence rates of brain tumours in children and is needed in order to show that our intervention, the campaign, has been effective at reducing the length of time taken to diagnose brain tumours.

Eventually it is hoped that National Cancer Intelligence Network (NCIN) will make it statutory for Neuro-oncology Units to submit this type of data. However this change in statutory practice may not occur for a few years.

Unless NICE undertake a partial or full update of the current Referral Guidelines for Suspected Cancer then it will be extremely challenging to encourage them to use our guidelines as 'business as usual'. However, evaluation of the resources, particularly the website will be monitored to see how many people are accessing it and will assess the feedback. Both CBTRC and SDBTT will continue to work on the project beyond March 2012 for two years having obtained external funding obtained not least due to the successes of this project to date.

### **RCGP E-learning Module**

CBTRC have been in discussion with RCGP to create an online e-learning tool about the role of the symptom card and website in consultations and the symptoms of brain tumours in children, which will help to promote our innovation further. This will be funded by CBTRC and will help to raise awareness of the guidelines. Furthermore, we will reach our target audience through a well-regarded online tool which will provide CPD points.

### **What do you see as the main challenges to future sustainability of your work?**

A minor point is that the team have not yet empirically tested the efficacy of the materials with the public and healthcare professionals. As part of sustainability, SDBTT will be assessing this.

Sustaining the awareness levels of the population is challenging without PR expertise and generous funding. SDBTT have put an impressive £350,000 into empowering patients and parents, media and PR as well as in disseminating the campaign materials, thus matching the Health Foundation funding. This means the campaign can continue until 2013 and will ensure a wider audience is reached across the whole of the UK.

### **What has been the impact of working through a clinical community and working with a national/regional partner?**

- Leadership from well respected clinicians is vital in securing interest from other medical professionals.
- The ownership of the project from the start has also proved to be essential in terms of carrying the campaign forward and extending the scope of work further. Much of the spread has been due to existing contacts and relationships of the clinicians and organisations involved.
- The clinical champions have been pivotal in collecting outcome measures, our Symptom Interval data. This could be challenging to sustain, when people have other priorities and commitments, we will sustain this by attending regular Special Interest Group Meetings where HeadSmart is

now an ongoing agenda item. We will continue to provide feedback, discuss the data and create innovative ways of sharing the learning outside of the group.

- Our contribution is for the Community and Clinical champions to join forces to help sustain a social movement, together they can help ensure that the health issue remains high on the government agenda.

A phrase that captures this is "Each of us individually does not count much. But together we are the strength of millions who constitute solidarity".

## **7. Plans for Spread**

### **7.1 Explain your plans for spreading the learning and outputs of this project.**

The Sustainability Plan (available on request) and the Marketing Plan outline many of the ways we intend to continue spreading the learning and outputs from this project, beyond March 2012.

- CBTRC and SDBTT will continue to raise awareness of the campaign beyond the life of the project, sharing the learning and outputs through continuing to attend conferences, deliver presentations, workshops and have stands and by liaising with Royal Colleges PR Managers.
- There are monthly HeadSmart Clinical and Community Champion Newsletters, which if popular, could be adapted for a more general target audience.
- NHS Live has enabled us to share campaign materials with over 11,000 frontline enthusiasts and appear in their e-newsletters and also encourages networking. See the link to HeadSmart below: [http://www.institute.nhs.uk/index.php?option=com\\_mtree&task=viewlink&link\\_id=4780&Itemid=4932](http://www.institute.nhs.uk/index.php?option=com_mtree&task=viewlink&link_id=4780&Itemid=4932)
- Finally, once we have more statistically reliable data, we will publish it and continue to seek awards for the project
- The next step for this project is to set a new target for speed of diagnosis across the EU Member States as a trigger for a systemic change in this field.

### **7.2 How are you going to promote your innovation and convince others of its value?**

#### **Outcomes will convince people of value**

There are multiple ways we are promoting our innovation and convincing others of its value. We have promoted our innovation by communicating with our stakeholders, attending conferences, delivering workshops, using clinical champions to help promote the project to peers. Word of mouth has been very powerful - communicating about our project through diffusion and dissemination.

Another useful technique is enabling clinical champions to share their learnings at meetings. Furthermore, having community and clinical champions working together in parallel helping to raise awareness could potentially be very effective.

The media and emotive news articles about personal experiences have helped to convince people of its value as indeed does the 'positive' story of a life saved help to show its value.

Spread to Cancer Networks - many have added to their websites and shared with local paediatricians including Gloucester, London, Somerset, Cheshire all have added our link to their news sections on the Cancer Network websites.

### **References from Clinicians**

References from clinicians outside the project will be influential in promoting the materials and convincing peers of its value for example:

*"...I have just seen two new patients in clinic with headache and followed the HeadSmart guidance (one reassurance – one review). It was really easy to follow and I suspect that will not lead to a huge increase in referrals of non-worrying children but pick up the ones you want. Congratulations on an excellent resource!!!"*

#### **Clinician, Children's Services at Nottingham University Hospital**

A thorough analysis of the health economic impact of the intervention and new way of working is essential in persuading commissioners and healthcare professionals of the benefits of the materials. This will be discussed further in the report in section 8.2

### **7.3 What advice would you give to someone attempting to replicate your work in another organisation / setting?**

A detailed analysis of lessons learned in the project has been created and can be seen in the appendices. This would include:

- Recruit a wider clinical champion network as early as possible
- Have discussions with NICE at earliest stage possible about support that can be provided
- Recruit clinical champions in primary care and allied health professionals
- Patient involvement from the start of quality improvement projects is valuable and essential. This ensures that users are able to set the quality criteria and inform product development. Furthermore, it encourages ownership of the project which is important for sustainability.
- Learning from others – the Meningitis Trust campaign has been influential in the development of our dissemination campaign.

### **7.4 What do you see as the main challenges to the future spread of your work?**

- Sustaining the enthusiasm and commitment from clinical champions
- Funding for evaluation
- It will be challenging to communicate effectively with RCGP unless the NICE Referral Guidelines for Suspected Cancer incorporate recommendations from our guidelines.
- Adding to this challenge, in the recent Equity and Excellence document, 'Liberating the NHS', it states that NICE will be responsible for developing over 150 Quality Standards and this needs to be considered by the team in the future.
- There has always been a challenge to hold people's attention with a campaign on a rare condition, and this may be the case particularly if there are other national health campaigns which affect more of the population.

## **8. Return on investment**

### **8.1 Can you estimate the cost of the intervention and the benefits accrued?**

We have used an awareness intervention to empower the parents and inform the healthcare profession, therefore the impact will be multi-dimensional and covers doctor-patient relationship, economic and long-term health outcomes. The financial benefits of earlier detection of childhood brain tumour are difficult to quantify at this stage. Over a quarter of long-term survivors of childhood central nervous system tumours have a significant disability. Reducing the disabilities experienced by a young child with a brain tumour (e.g. by reducing learning difficulties or visual impairment etc.) will lead to both increased productivity in adult life and reduced dependence on state support, which should result in considerable savings over a life-time.

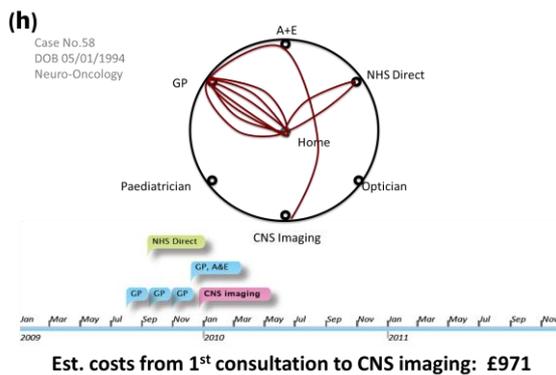
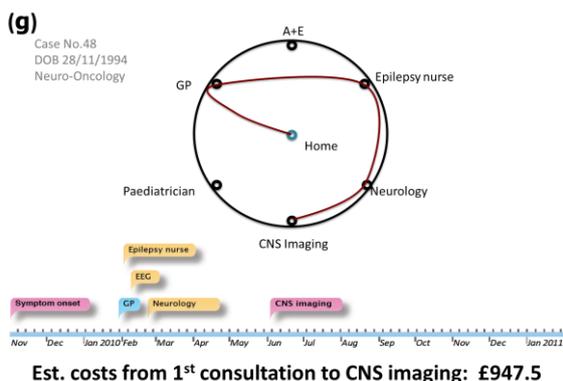
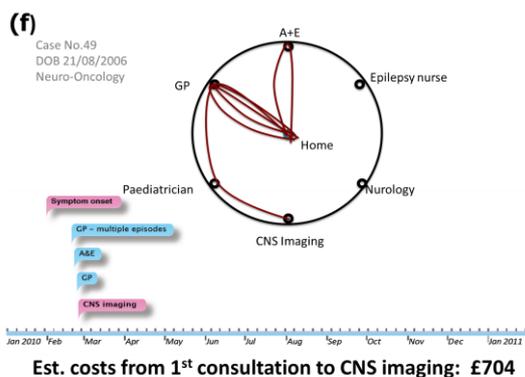
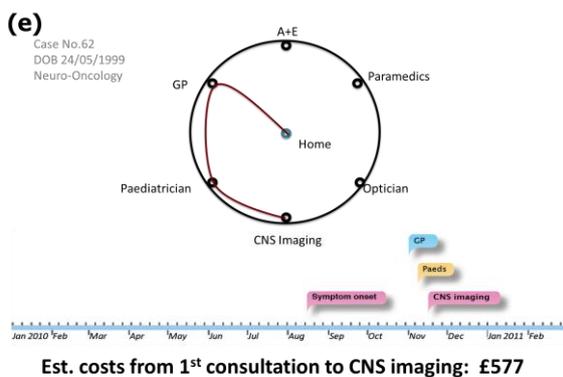
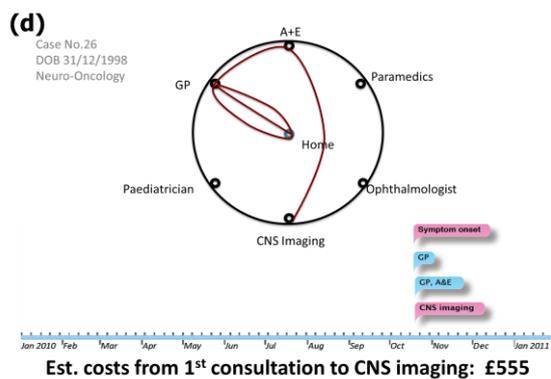
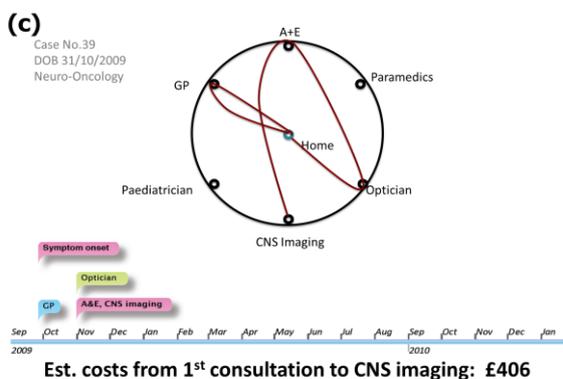
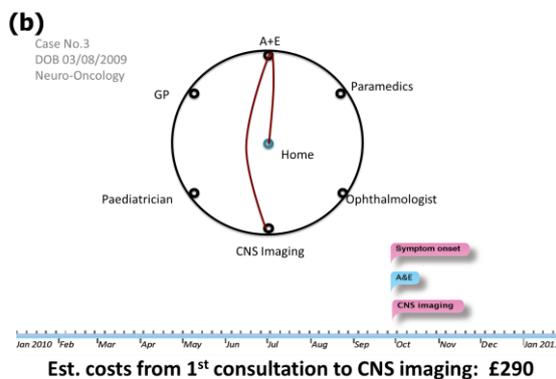
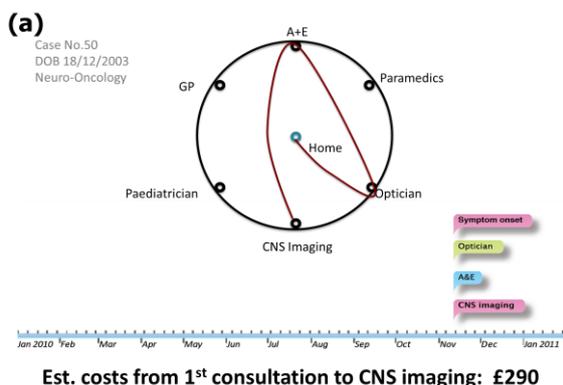
The quality of cost-effectiveness analyses to try and measure this, is highly dependent on the quality of the effectiveness data that is available to be used; and in some ways this has been the weakest area of the project. This is because benefits are not going to be realised until 10-15 years in the future and at the moment, there isn't the drive in the UK health service to collect long-term disability data on children with brain tumours. We conducted a literature search concerning health economics of brain tumour and its diagnosis in children and young people across 11 databases. We concluded that there is a lack of studies on this topic.

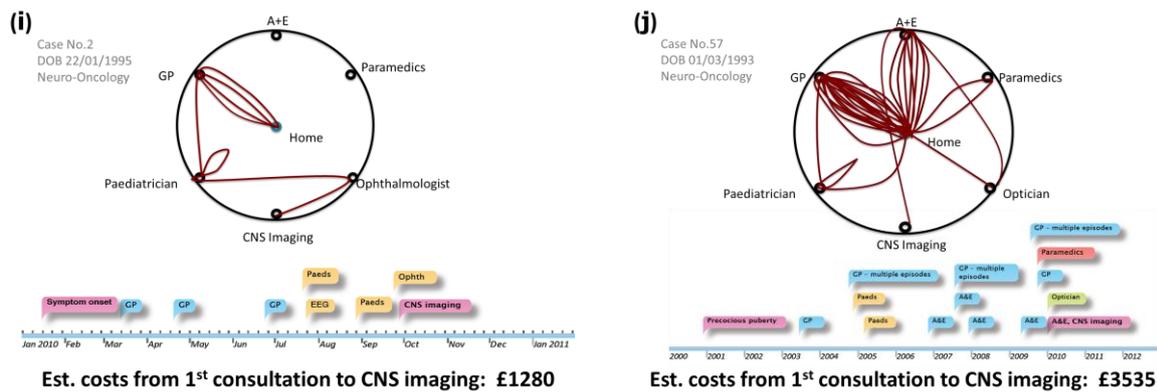
Compared with cost-effectiveness analyses, which require population based or robust data, identifying direct service costs for individual patient is less problematic. Based on the information collected in our service evaluation project, we managed to map the referral pathways of 10 paediatric brain tumour patients and estimated service cost according to National Schedule of Reference Costs 2010-2011. At individual level, the cost difference between best practice pathway (Figures 17a or 17e) and the most complex pathway (Figure 17j) could be 6 times or more (see Figure 17). It is intuitive that the service cost from symptom onset to diagnosis will be less if we are able to drop the redundant steps demonstrated in these "handoff diagrams".

As for treatment costs, it can be predicted that the successful implementation of the Guideline will save money in the long term by reducing costs to the health service in primary and secondary care (through lower consultation costs), we do not have information yet on the cost changes in investigations, although preliminary regional monitoring in imaging activity has not identified major changes. The change in costs to society from reduced levels of disability could be predicted, if our hypothesis that "earlier diagnosis prevents neurological damage" is supported. It was never intended that we measure these aspects within the timeframe of the project. They are the focus of existing grant applications for epidemiological research using GP Research Database linked to Cancer Registry and Hospital Episode Statistics (HES) databases, which have been initiated at the London School of Hygiene and Tropical Medicine under the combined supervision of Professor Michel Coleman and Professor David Walker, working with Dr Thomas Chu in his PhD project. A second project studying childhood cancer referrals in the GPRD is in progress at the University of Bristol, they are in the process of reporting their work comparing symptoms in both cases and controls.

We are analysing the cost of the intervention by developing a decision tree, working with Health Economists at NCC-WCH. This has been challenging thus far, because it is difficult to obtain the data required to build a model, upon which predictions or future research could be based. On reflection, the project team could have anticipated the weakness in this area and identified their lack of technical ability and resource to tackle such a cost-benefit analysis in this field. Establishing collaborations with groups, expert in the field was the right strategy. The working relationship that has been established

with the Department of Health Economics at University of Nottingham, the NCC-WCH, the London School of Hygiene and Tropical Medicine and the Departments of Paediatric Oncology and Epidemiology at the University of Bristol are valuable outputs for the sustainability programme.





**Figure 17:** Referral pathways from symptom onset to diagnosis and estimated direct service cost of 10 patients

### 8.2 What have been the cost implications to your work?

What is the case is that the project has not increased costs for the NHS? We have not identified evidence of increased cancer 2 week wait referrals, we have not identified increase in imaging referrals, we have not identified evidence of excess GP consultation or unnecessary referrals to paediatricians in the East Midlands. Costs of dissemination of HeadSmart materials and development of the website have been borne by the Project and charity budgets. This guideline aims to reduce the time to imaging, rather than increase the number of children who need to be images, it provides specific advice on when to reassure. This combination of factors was designed into the guidance in order to avoid large numbers of additional children being imaged. At this stage we believe that this strategy has been successful.

### 8.3 What were the main difficulties you encountered in identifying cost and benefits of your work?

It is too early to measure the disability outcome and evaluate the effectiveness of the HeadSmart, the health economic model aims to forecast the potential benefit and would require some data about current practice as baseline information.

During the development of the health economic model and current phase of data collection, we encountered a few main difficulties:

- Identifying potential benefits  
There are many types of brain tumours and they all behave differently, therefore patient's journey to diagnosis and the number of healthcare professionals involved could vary. It is likely that HeadSmart will benefit patients with certain type of tumours (e.g., low grade / slow growing tumours with slow progression of neurological symptoms such as vision loss). Its impact upon faster growing tumour which present more precipitously is less predictable e.g. medulloblastoma, high grade glioma. This latter group's prognosis is determined by their sensitivity to intensive therapies and the neurological risk of their anatomical location. It is therefore hard to generalise the experience and identify the cost and benefits in all tumour types.

We conducted a literature search on the current health economic research on brain tumours in children. 11 electronic databases were searched (including Medline, Embase, EconLit) and only 50 articles were deemed relevant for full review. It is clear that there is lack of studies linking costs and brain tumours, especially long term outcomes, both at the local and national level; and there is no any kind of decision modelling and modelling long term outcomes of paediatric brain tumours.

- Obtaining data to feed the health economic model  
To forecast the potential economic impact of HeadSmart campaign we would need some information on current status to feed the model. For instance, how patients with different brain tumour signs and symptoms move down referral pathways (e.g., direct referral, no referral and symptom resolved or delayed in referral and brain tumour rate in each group), which we know very little about and there was no published literature.

As there is scarce information available from literature, we believe the best way to obtain reliable, robust data was to get the information from GP Research Database. The work being carried out by Dr Chu in his thesis was linked to an English cohort of patients with linked records between GPRD, HES and national cancer registry permits accurate case ascertainment from the cancer registry, proven linkage to selected set of GP practices in England and details of hospital treatments leading up to and after diagnosis. Whilst the data is a subset of a national cohort it does provide an opportunity to model referral pathways in selected time periods using contemporaneously and prospectively collected data about every consultation in primary and secondary care prior to diagnosis. Dr Chu's project uses this linkage. A second group, working at Bristol University also used GPRD databases but without the link to the cancer registry or HES. Their project, which is in the final stage of reporting, prior to publication, has included control case data from the GPRD. This will permit the relative frequency of different symptom groupings between those ultimately diagnosed with brain tumour and those without. We have established links with both these projects and the data from them will assist greatly in further developing the model. We anticipate it to become fully available for such an exercise by June 2012.

## 9. Conclusions

The original aims of Closing the Gap through Clinical Communities were to:

- build the knowledge and skills of clinical teams in how to make improvements in the quality of care
- contribute to the creation of a systematic body of knowledge concerning how best to engage clinicians in quality improvement activity
- stimulate learning about quality improvement amongst health professionals
- support clinical communities to make demonstrable improvements in quality by tackling known gaps between best practice
- support routine delivery of care

### **Reflecting on the previous sections of the report how well do you feel the project met these aims?**

- We have built on the knowledge of clinical teams through the website and associated materials and by presenting at various meetings and conferences this has begun to lead to earlier diagnosis of brain tumours in children.
- We have contributed to a systematic body of knowledge on engaging with clinicians in quality improvement through publications and presentations at professional conferences and events. Whilst these are publically available though, it would be fair to say that we have not deposited our QI learnings to a central or systematic knowledge base.
- We have stimulating learning by sharing our experience in the course of the projects not just of HeadSmart itself but also the way in which we have developed the campaign – learnings and benefits of quality improvement as a methodology.
- We are able now to help practitioners to reassure, review, refer, where appropriate, using the educational tools provided. The project has been designed to empower patients with their doctors to share decision-making when it counts.
- We have supported the routine deliver of care by providing continued access to the diagnostic tool online as well as e-learning module as well as through empowering patients to share their concerns with the health care provider using accredited materials.

### **Final statement**

The HeadSmart team are immensely proud of the achievements made during the Closing the Gap project. We would like to thank all partners involved with the project, without whom, the success would not be possible.

That the success of the HeadSmart campaign has been recognised across Europe is evidence of its value in changing outcomes for children with brain tumours. The campaign in the future will be launched to raise awareness of brain tumours in children and adolescents, based upon the UK-based 'HeadSmart' campaign partnering with the International Confederation of Childhood Cancer Parent Organisations and the SIOP Brain Tumour Group.

There is further work to be undertaken to ensure parents and carers from across the socio-economic spectrum are aware of the signs and symptoms – that every family has a card next to the Calpol or in their medicine cabinet. This will be the primary aim for the next two years.

Combined with achievements to date and the continuing plans for health professionals, there is no doubt we will reduce average diagnosis times from 3 to 1 month.

We would also like to thank the Health Foundation for providing funding for this important project, and we hope that we have clearly demonstrated value for money by improving the patient experience and reducing the length of time taken to diagnose brain tumours in children.

## **Figures and Tables**

**Figure 1:** An example of short symptom interval and direct interval

**Figure 2:** An example of patient with medium symptom interval and referral pathway

**Figure 3:** An example of delayed referral

**Figure 4:** Driver Diagram

**Figure 5:** Use of symptom card in child and family consultation

**Figure 6:** Team Roles

**Figure 7:** Children's Cancer & Leukaemia Group Treatment Centres

**Figure 8:** Healthcare professionals' perception of average length of symptom interval

**Figure 9:** Confidence in ability of recognising brain tumour symptoms.

**Figure 10:** Number and percentage of follow up survey participants

**Figure 11:** Symptom interval of brain tumour cases diagnosed in 2011

**Figure 12:** Symptom interval by month of diagnosis and centre

**Figure 13:** Comparison of median symptom interval (in weeks)

**Figure 14:** Symptom interval comparison – other UK studies & HeadSmart

**Figure 15:** Categorisation of delay

**Figure 16:** Front page of interactive education module

**Figure 17:** Referral pathways from symptom onset to diagnosis and estimated direct service cost of 10 patients

**Table 1:** Team members

**Table 2:** Key results of the pre-launch public awareness baseline surveys (February 2011) and post launch follow-up survey (September/October 2011).

**Table 3:** Key results of the pre-launch professional baseline surveys (March/April 2011) and post launch follow-up survey (November 2011-February 2012).

**Table 4:** Symptom interval comparison - Pre HeadSmart project, pre- and post HeadSmart launch

**Table 5:** Patient's place of care at the time of CNS imaging ordered and usage of urgent cancer referral

**Table 6:** List of media links created by public launch

**Table 7:** Barriers and limitations of data collection – symptom interval

**Table 8:** Barriers and limitations of data collection – public awareness

**Table 9:** Barriers and limitations of data collection – professional awareness

**Table 10:** HeadSmart Materials Dissemination (June 2011 – March 2012)

## **Appendices (sent on CD already)**

### Policy

1 - List of clinical champions

### Evaluation

2 - Copy of SI data collection form

3 - Public Awareness Survey

4 - Professional Awareness Survey

5 - Results from Public Awareness Survey

6 - Results from Professional Awareness Survey

7 - Results from SI data collection

8 - Instruments and procedures (qualitative, quantitative, or mixed) used

9 - Benefits Table

### Website

10 (a-c) - Website Hits Reports

### Marketing

11 - Media Coverage Booklet

12- HeadSmart Poster

13- HeadSmart Leaflet

14 - HeadSmart Symptom Card

15 - Slidesets

16 - Example of workshop feedback

17 - Press Release

18 - E Newsletter to Clinical Champions

19 - Marketing Plan

20 - Positive case story following campaign - from SDBTT

### Meetings and Events

21 - Table of presentations

22 - Table of Events attended

### Project Closure

23 -Lessons Learned Report