

Impact case study (REF3)

Institution: University of Nottingham		
Unit of Assessment: UoA1		
Title of case study: HeadSmart campaign accelerates diagnosis of children's brain cancer in the United Kingdom and internationally		
Period when the underpinning research was undertaken: 2004-2017		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
David Walker	-Professor in Paediatric Oncology	-1990-present
Sophie Wilne	-Paediatric Oncology Consultant	-2004-2006 (Research Fellow), 2010-2020 (Honorary)
Jo-fen Liu	-Research Assistant	-2009-2012, 2014-present
Dhurgsharna Shanmugavadivel	-NIHR Doctoral Research Fellow	-2015-present
Period when the claimed impact occurred: 2014 - 2020		
Is this case study continued from a case study submitted in 2014? No		
<p>1. Summary of the impact In 2008 the University of Nottingham's Children's Brain Tumour Research Centre (CBTRC) developed new NHS evidence-based guidelines and, in 2011, launched a successful national awareness campaign entitled HeadSmart. This campaign led to a significant and sustained reduction of time taken to diagnosis for children's brain tumours by 53% (a median decrease of 7.7 weeks). Accelerating diagnosis reduces adverse outcomes including blindness, paralysis and cognitive deficits. Since 2014, the CBTRC's research and HeadSmart has continued to expand public awareness, resulting in a dedicated Government Task & Finish group and increased funding for brain tumour research. The HeadSmart campaign has increased GP confidence and accuracy, as well as public awareness, of childhood and teenage cancers. HeadSmart is now widely-recognised and acclaimed nationally and has been emulated internationally.</p>		
<p>2. Underpinning research Why did this project happen? Brain tumours account for 20-25% of all cancers in the first 25 years of life, making them the second most common cancer in childhood and killing more people under 40 than any other cancer. Delays in diagnosis are common. In 2013, 58% of high-grade brain tumours in children were diagnosed as an emergency – more than any other cancer. These delays increase the risk of premature death for some patients, and lifelong disability in over 60%. Reducing delays in diagnosis is therefore vital to increasing survival and reducing disability. Public concerns about diagnostic delays, expressed in the media, in the courts and in Parliament, have been very prominent and have resonated with professional concerns. However, brain tumour research is historically under-funded, representing just 0.52% of the Government's total spend on cancer. Additionally, as brain tumours remain relatively rare, GPs see few cases and thus experience difficulty in recognising symptoms, leading to inaction or misdiagnosis. HeadSmart aims to improve awareness amongst the public and healthcare professionals while addressing the imbalance between the severity of brain tumours and the lack of government support.</p> <p>Identifying ineffective referral, creating guidelines, and launching HeadSmart: The initial research on referral practice conducted by Professor David Walker, Dr Sophie Wilne, Dr Jo-Fen Liu, and others established that the median Total Diagnostic Interval (TDI – the time from symptom onset to diagnosis) in the UK was 14.4 weeks (comparable figures in the US and Poland were 5 weeks, and Canada, Switzerland and Israel were less than 8 weeks) and had not changed over the previous 25 years [1, 2]. It was identified that multiple ineffective referrals between home, primary, and secondary care were occurring prior to diagnosis, particularly in patients with the slowest growing tumours. The decision was taken to produce new clinical referral guidelines for the UK, and to develop and run an awareness campaign.</p> <p>A systematic literature review and meta-analysis of previous studies describing symptomatology was conducted [3], which, together with information from referral studies, supported a Delphi consensus process with over 150 experienced healthcare professionals</p>		

and parents. The resulting NHS evidence-based guidelines were produced by the Children's Brain Tumour Research Centre (CBTRC) in 2008, received NICE NHS Evidence accreditation in 2010, and were followed by the launch of the HeadSmart campaign in 2011. Since its launch, HeadSmart has raised awareness of the signs and symptoms of brain tumours, provided clear diagnosis guidelines, and helped reduce the TDI from a median of 14.4 to 6.7 weeks between 2006 and 2013 [4]. However, the TDI varied greatly between different tumour subtypes and age groups, with survival rates in adolescents comparatively worse than in younger children.

Addressing problem areas: the next research step

A study conducted by Dr Shanmugavadivel, Ms Liu, Ms Murphy (BMedSci student), Dr Wilne and Professor Walker on behalf of HeadSmart in 2011-2013 [5] revealed that low grade, centrally-located tumour subtypes had the longest delays, with the greatest contribution of this delay stemming from the SI (system interval – the time from patient presenting to a healthcare professional to diagnosis). This prolonged SI suggests that although patients are presenting to healthcare services, these cases posed a diagnostic challenge to healthcare professionals, highlighting the need for further work to develop both GP and specialist awareness and knowledge. Furthermore, adolescents in the 12-18 age group experienced significantly longer delays compared to younger children, with a TDI of 12.1 weeks (compared with 8 weeks for the 5-11 age group and 6 weeks for the 0-5 age group). In this group, the PI (patient interval – the time between symptom onset and initial presentation to a healthcare professional) was the largest contributor, suggesting that adolescents are less likely to recognise the nature or seriousness of their symptoms, and/or less likely to seek healthcare assistance. Consequently, there was a need to engage this age group in order to give them the knowledge and resources needed for them to seek guidance from a healthcare professional. As a result of these findings, ongoing development of the HeadSmart campaign has aimed to continue developing public awareness, while also providing more specialised guidance to health practitioners to help improve confidence in diagnosis.

Additionally, a review of new evidence in the literature was carried out and increasing head circumference was newly identified as the commonest clinical sign in the under 3 age group, and incorporated into to the revised guideline published in 2017 [6].

3. References to the research

- [1] Wilne S, Ferris R, Nathwani A, Kennedy C. The presenting features of brain tumours: a review of 200 cases. *Arch Dis Child*. 2006; 91(6): 502-506. DOI:10.1136/adc.2005.090266
- [2] Wilne S, Collier J, Kennedy C, Jenkins A, Grout J, Mackie S, Koller K, Grundy R, Walker D. Progression from first symptom to diagnosis in childhood brain tumours. *European Journal of Pediatrics*. 2012; 171: 87-93. DOI:10.1007/s00431-011-1485-7
- [3] Wilne S, Collier J, Kennedy C, Koller K, Grundy R, Walker D. Presentation of childhood CNS tumours: a systematic review and meta-analysis. *Lancet Oncol*. 2007; 8: 685-695. DOI:10.1016/S1470-2045(07)70207-3
- [4] Walker D et al. A new clinical guideline from the Royal College of Paediatrics and Child Health with a national awareness campaign accelerates brain tumor diagnosis in UK children - "HeadSmart: Be Brain Tumour Aware". *Neuro Oncol*. 2016; 18(3): 445-54. DOI:10.1093/neuonc/nov187doi:10.1093/neuonc/nov187.
- [5] Shanmugavadivel D, Liu JF, Murphy L, Wilne S, and Walker S. Accelerating diagnosis for childhood brain tumours: an analysis of the HeadSmart UK population data. *Archives of Disease in Childhood*. 2019. DOI: 10.1136/archdischild-2018-315962
- [6] Shanmugavadivel D, Liu JF, Murphy L, Wilne S, and Walker S. Systematic Literature Review to Study Symptomatology and Population based Total Diagnostic Interval of Children presenting with Brain Tumours. *Neuro-Oncology*. 2016; 18.3. DOI:10.1093/neuonc/nov071.8

Grants

- [G1] 09/2003-02/2006 Walker et al 'Tracking delays in diagnosis of brain tumours in childhood'. Samantha Dickson Brain Tumour Trust /Community Fund (Lottery): GBP105,000
- [G2] 09/2006-08/2007 Walker et al 'Pathways II Introduction of guidance to shorten symptom interval'Samantha Dickson Brain Tumour Trust GBP44,479

[G3] 11/2009 -10/2011 Walker et al 'Brain Pathways: Promoting an earlier diagnosis of brain tumours in children'. GBP408,472 (Health Foundation GBP392,472 and The Brain Tumour Charity GBP16,000).

[G4] 2003-2018 David Walker & Richard Grundy, CBTRC Programme Grant, The Brain Tumour Charity GBP1,500,000 (within this, a programme grant awarded for HeadSmart post-doctoral fellowship).

Awards: National Lottery Awards - Best Health Project 2017.

4. Details of the impact

As a result of the research conducted by Professor Walker and his team, the University of Nottingham's CBTRC developed new NHS evidence-accredited referral guidelines, published in 2008, to reduce diagnostic delays for children with brain tumours. Their messages were disseminated through an awareness campaign, 'HeadSmart: Be Brain Tumour Aware', launched in 2011. The awareness campaign targeted the public and healthcare professionals in an effort to increase awareness of brain tumour symptoms in children through educational and promotional materials. The campaign included the development of a network of Clinical Champions and Community Champions who helped to communicate the aims of the campaign in treatment centres and local communities. Three months post-launch, 11% of the UK population (over 14 million) and 73% of paediatricians were aware of HeadSmart, and diagnostic confidence among paediatricians had risen from 32% to 54% **[4]**. The time from symptom onset to diagnosis reduced from 14.4 weeks in 2006 to 6.7 weeks in 2013 **[4]**.

Improving practitioner confidence through the 2016 RCGP special project

Since **2014**, the HeadSmart campaign has continued to grow public awareness and educate practitioners to better recognise the symptoms of brain tumours. In **2016**, the HeadSmart team organised a one year special project in partnership with the Royal College of General Practitioners (RCGP) to improve awareness of symptoms amongst GPs. This project resulted in two workshops in London and Manchester, and a RCGP online toolkit which was launched in November **2016**. From their research the HeadSmart team developed a new decision support tool to allow clinicians to review brief checklists derived from the NICE-accredited clinical guidelines in order to decide on what actions to take next and whether a patient should be referred for an MRI **[A]**. As children often pass through a variety of specialists before receiving a diagnosis, a poster was also developed to help specialists recognise subtle or general symptoms that may present to their sub-speciality, and link them to the location of a potential brain tumour **[A]**. Previous research had signalled that despite the campaign's general success, only 26% of GPs were aware of HeadSmart after its launch in 2011. An online survey carried out before the RCGP project confirmed that 'only 28% of GPs said they were aware of relevant guidance' with GPs rating their diagnostic confidence for childhood brain tumours as 4.8/10. In **2017**, a follow up survey after the project demonstrated an increase of 24% in GP awareness, with their confidence rating increasing to 5.7/10 **[B]**. Furthermore, pre- and post- project assessments of GPs recognition of symptoms showed that the 'number of GPs correctly identifying head tilt as a concerning sign rose from 42% to 70%', demonstrating improved knowledge in the GP community **[B]**.

Improving public awareness through relaunch of the HeadSmart Campaign

In **2017**, the clinical guideline (originally NICE NHS Evidence accredited in 2011) was reaccredited and relaunched by the Royal College of General Practitioners (RCGP), incorporating new findings **[C]**. Responding to the most recent research **[4, 5]**, the HeadSmart campaign was also re-launched in **2017** with the aim to continue raising public awareness, particularly targeting the adolescent age group. The HeadSmart website was redesigned in consultation with TYA (teenage and young adolescent) advisors to what is more appealing and accessible to this age group. The campaign was given a new logo and branding, and further work focused on school visits, an increasing social media presence, and the use of celebrity ambassadors as role models. As of November **2020**, HeadSmart's Facebook page has received 36,115 likes, while the Twitter page has 5,823 followers. The HeadSmart animation on YouTube has been viewed 7,112 times. Previously, 4 months following the initial launch of the campaign in 2011, a survey showed that 11% of the public were aware of HeadSmart (HeadSmart Be Brain Tumour Aware. A new clinical guideline' (**2016**) **[4]**. Data from **2017** shows that public awareness of HeadSmart has grown to 28%, showing a significant increase **[D, page 42]**.

Accelerating Diagnosis: Impact on Patient Outcomes

Delay in the diagnosis of children with brain cancer can result in substantial adverse impacts upon quality of life (e.g., blindness, paralysis, cognitive deficits, and shunt malfunctions). Based on University of Nottingham data collection, the median TDI has shown a significant reduction from pre-campaign levels of 53%, from 14.4 weeks to 6.7 weeks in 2013, 2 years post launch. It has continued to reduce to 6.5 weeks in **2015**, demonstrating a continued, steady decline and improvement **[E, slides page 11]**. Moreover, the system interval which is the time from seeing a healthcare professional to getting a diagnosis reduced from a median of 3.3 weeks pre-launch to just 1 week in **2015 [E, slides page 11]**. In real terms this means on average, a patient receives a diagnosis within 1 week of first seeing a healthcare professional which has a large impact on patient outcomes. Unfortunately, due to data access issues, there is currently no TDI data available post-**2015**. HeadSmart is effective in shortening the time interval from first symptoms to definitive diagnosis, which can reduce adverse outcomes, including blindness, paralysis and cognitive deficits **[F]**.

Stimulating Public Policy Debate:

The increased public awareness around brain tumours, due in large part to the success of the HeadSmart campaign and the political influence of Professor Walker's research on brain tumour policy groups, has led to calls from the public for the government to do more to tackle brain tumours, which culminated in an ePetition receiving over 120,000 signatures in **2015**. The UK All Party Parliamentary Group (APPG) concerned with brain tumours, of which Professor Walker is a founding member, supported the Petitions Committee report (**2016**) and the subsequent Parliamentary Debate in April **2016 [G, H]**. The Petitions committee, which referenced HeadSmart on numerous occasions, highlighted how HeadSmart 'has managed to improve the time taken between people presenting to their GP and diagnosis' **[G]** and 'was impressed by the HeadSmart campaign which shows how guidance can have such a positive impact in a relatively short space of time without over burdening GPs' **[H, page 24]**. The success of HeadSmart and the incorporation of brain tumour symptoms into the NICE guidelines were seen as vital to ensuring early diagnosis which 'would greatly increase survival rates and improve the quality of life of those who are diagnosed' **[G]**.

As a result of the debate, a UK Government-commissioned Brain Tumour Research Task and Finish Group was established, which brought together clinicians, charities, researchers, patients' carers and officials to look at how to remove barriers to brain tumour research. Professor Walker was one of only two paediatricians in the group and the HeadSmart campaign played a prominent role in discussions. The group published a report in **2018**, which emphasised that brain tumour research is a major priority for the UK. It highlighted the need to grow research capacity and collaboration, stressing that the Government should ensure that adequate research funding is provided. The report also recognised the availability of data as a significant issue, highlighting the HeadSmart campaign as an example where such barriers had impeded research efforts and had therefore 'directly impacted analysis of the diagnosis pathway' **[I, page 25]**. The report encouraged NHS trusts and other bodies to give wider access to data, in line with the wishes of patients. As a result of this report, the Government announced that it planned to double its investment in brain cancer research with a GBP40,000,000 'Dame Tessa Jowell Brain Cancer Research Mission', which is part of a GBP65,000,000 research package that includes a funding commitment of GBP25,000,000 from Cancer Research UK **[J]**.

International Impact: Implementing HeadSmart Strategy Abroad

Following the success of HeadSmart in the UK, health leaders from across the world have been enthusiastic to emulate the initiative, with international countries drawing on HeadSmart's successful strategy **[D]**.

In Denmark, medical practitioners and researchers contacted Professor Walker after learning about the UK HeadSmart initiative and its success and with the intention of 'implementing a similar strategy in Denmark': 'We contacted Professor David Walker to learn from his experience in setting up an awareness campaign' and Professor Walker and his research team 'shared the detailed strategies of the HeadSmart programme with our research team, offered support, and most kindly answered all our questions'. Denmark now intends to launch a similar strategy, 'adapted to a Danish setting'. Furthermore, 'there is also a growing awareness of the HeadSmart initiative in Denmark' and 'an introduction to the HeadSmart

initiative and website has been part of the training [to become a paediatrician] for a couple of years now', further establishing that the HeadSmart initiative and Professor Walker's research are 'of great inspiration and importance' [K].

In Jordan, the '[HeadSmart Jordan](#)' project was launched in 2020 as a direct result of HeadSmart's UK success and communication with David Walker: 'After securing a major grant from My Child Matters [...] we decided we wanted to collaborate officially with HeadSmart'. As well as drawing on Professor Walker's expertise as a researcher in this area, practitioners in Jordan 'are using the same medical information from the UK HeadSmart posters and cards, adapted to our local conditions and translated to Arabic language. The use of these resources is important as we could not regenerate Professor Walker's substantial scientific data with our limited resources'. 'With no doubt, the HeadSmart initiative and Professor Walker's work has inspired our project and was vital in its inception' [L].

Expanding on HeadSmart's success in other areas of cancer clinical practice

Following on the success of the HeadSmart campaign, researchers and practitioners hope to emulate the initiative to tackle other childhood cancers. The '[ChildCancerSmart](#)' initiative aims 'replicate [HeadSmart's] success' by addressing 'delays by developing high quality guidance on cancers in children and young people, and produc[ing] awareness tools for a national awareness campaign to promote earlier diagnosis'.

5. Sources to corroborate the impact

- [A] HeadSmart decision support tools, sub-speciality poster and other healthcare resources. Available: <https://www.headsmart.org.uk/clinical/>
- [B] Chellaswamy R, Shanmugavadivel D, Walker D. Diagnosing and excluding brain tumours in children: assessing awareness amongst GPs of available resource and developing an online toolkit for primary care. Poster presented at the RCGP conference 6-8th October 2017.
- [C] 'The Brain Pathways Guideline: A Guideline to assist Healthcare Professionals in the assessment of children who may have a brain tumour' 2017 (https://assets.headsmart.org.uk/live/media/filer_public/8e/c3/8ec36f34-1c0d-4c3c-bc5f-706570b7af34/brain_pathways_guidelines_final.pdf)
- [D] Walker, D. (Ed.), Perilongo, G. (Ed.), Taylor, R. (Ed.), Pollack, I. (Ed.). (2021). Brain and Spinal Tumors of Childhood. Boca Raton: CRC Press, Available upon request, DOI: [10.1201/9781003090120](https://doi.org/10.1201/9781003090120)
- [E] Shaarna Shanmugavadivel, Jo-fen Liu, Sophie Wilne, David Walker, EPID-04. Reducing time to diagnosis of Paediatric Brain tumours in the UK – headSmart awareness campaign (www.headsmart.org.uk), *Neuro-Oncology*, Volume 20, Issue suppl_2, June 2018, Page i81, DOI: [10.1093/neuonc/ny059.237](https://doi.org/10.1093/neuonc/ny059.237)
- [F] Coven S, Stanek J, Hollingsworth E, Finlay J. Delays in diagnosis for children with newly diagnosed central nervous system tumors. *Neuro-Oncology Practice*. 2018;5(4):227-233. DOI: [10.1093/nop/npy002](https://doi.org/10.1093/nop/npy002)
- [G] Minutes from the Brain Tumours Petitions Committee Debate, 18 April 2016: <https://hansard.parliament.uk/commons/2016-04-18/debates/16041811000001/BrainTumours>
- [H] 'Funding for research into brain tumours', Petitions Committee Report (2015-2016). <https://publications.parliament.uk/pa/cm201516/cmselect/cm petitions/554/554.pdf>
- [I] Report of the Task and Finish Working Group on Brain Tumour Research (2018) <https://www.gov.uk/government/publications/brain-tumour-research-task-and-finish-working-group-report>
- [J] Government announces £40 million for brain cancer research in honour of Tessa Jowell. <https://www.gov.uk/government/news/government-announces-40-million-for-brain-cancer-research-in-honour-of-tessa-jowell>
- [K] Testimonial from Doctor of Medicine, Aarhus University Hospital and Head of Childhood Cancer Research Group, Danish Cancer Society Research Center, Denmark.
- [L] Testimonial from Paediatric Neuro-oncologist at King Hussein Cancer Centre, Jordan