

Guidance producer: **Children's Brain Tumour Research
Centre**

Guidance product: **The brain pathways guideline**

Date: **23 February 2017**

Version: **1.3**

Final Accreditation Report

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Introduction

The NICE Accreditation Programme recognises organisations that demonstrate high standards in producing health or social care guidance. Users of the accredited guidance can therefore have high confidence in the quality of the information. Organisations may publicly display a seal of approval called an Accreditation Mark for 5 years after their processes have been accredited. The process for accrediting producers of guidance and recommendations for practice is described in the [process manual](#).

Accreditation recommendation

NICE has renewed accreditation of the process used by the **Children's Brain Tumour Research Centre** to produce **The brain pathways guideline**. The renewed accreditation is valid until **21 July 2021** and applies to guidance produced using the processes described in '**The brain pathways guideline**' (2016). The original accreditation term began on **21 July 2011**.

Background to the guidance producer

The Children's Brain Tumour Research Centre (CBTRC) was established in 1997 and is part of the University of Nottingham. Its aims are to conduct research into children's brain tumours and methods of diagnosis and treatment, to establish new treatments and improve survival rates.

As part of this work, the CBTRC has undertaken a programme of research, guideline development and implementation, to raise healthcare professionals' awareness of the signs and symptoms associated with children's brain tumours, and reduce the time from symptom onset to diagnosis. The output of this programme is 'The brain pathways guideline' (2016). The focus of the guideline is the diagnosis of brain tumours, rather than their subsequent management.

Summary

The Accreditation Advisory Committee considered that the processes used by Children's Brain Tumour Research Centre to produce the brain pathways guideline demonstrated compliance with 25 of the 25 criteria for accreditation.

The scope and purpose of the guidance is clear. Guidance development involves relevant professionals, lay people and target users. Evidence is gathered and appraised systematically and it is clear how recommendations are developed, taking risks and benefits into account. There are processes for external review of the guidance and for both scheduled and ad-hoc updating of the guidance.

The guidance provides clear recommendations and any options for imaging where applicable. The dates of the current review, systematic searches and the next scheduled review are provided. The content and format of the guidance are suitable for the intended users. Quick reference guides and patient information symptom cards are included in the guidance. Barriers to implementation are discussed in the guidance and monitoring of the time from symptom onset to diagnosis is ongoing. The funding source is transparent and editorial independence is maintained. All those directly involved in development are required to declare any interests, which are managed according to a defined policy. The possibility of bias is accounted for overall.

Suggestions for improving the process used to develop the brain pathways guidance include:

- improving the transparency around the decisions and actions taken to manage some declarations of interest

Professor Martin Underwood

Chair, Accreditation Advisory Committee

February 2017

Implementation

Following accreditation, guidance from the accredited producer will be identified on NICE Evidence Search by the Accreditation Mark. The accredited guidance producer is also granted a royalty-free, worldwide licence to use the NICE Accreditation Mark in accordance with the Conditions and Terms of Use. Providing these conditions are met, a guidance producer's accreditation will last for a further 5 years from the expiry of the previous accreditation term. Guidance already produced under the previous accreditation decision continues to be accredited.

Accredited guidance producers must take reasonable steps to ensure the accredited processes are followed when generating the type of evidence for which they are accredited. Accredited guidance producers should have quality assurance mechanisms in place and must inform NICE accreditation within 30 days if any significant change is made to a process.



Figure 1: The NICE Accreditation Mark

Appendix A: NICE Accreditation analysis

The Accreditation Advisory Committee considered the following analysis of the guidance producer’s compliance with NICE Accreditation criteria, which covers 6 discrete domains. The full analysis leading to the accreditation decision is shown below.

Criterion	Evidence for meeting the criterion	Accreditation decision	
Scope and purpose	Does the guidance producer have a policy in place and adhered to that requires them to explicitly detail:		
	1.1 Overall objective	The style guide ¹ states that the overall aims of the guideline should be clearly stated, and provides an example of how this may look. The introduction of the guideline ² describes its overall aim to reduce the symptom interval experienced by children with brain tumours.	Criterion met
	1.2 The clinical, healthcare or social questions covered	The style guide ¹ states that the key questions addressed by the guideline should be stated, and provides an example of how this may look. The introduction of the guideline ² states the key questions addressed by the guideline, with more details provided in the recommendations sections for different topics.	Criterion met
	1.3 Population and/or target audience to whom the guidance applies	The style guide ¹ states that the target audience and the target population should be clearly stated. The guideline ² describes its target population and target audience.	Criterion met

Criterion	Evidence for meeting the criterion	Accreditation decision	
1.4	Guidance includes clear recommendations in reference to specific clinical, healthcare or social circumstances The style guide ¹ requires clear recommendations for children of different ages with specific signs and symptoms. The main guideline ² , including its quick reference version and the age-specific symptom cards all provide clear recommendations in reference to specific circumstances.	Criterion met	
Stakeholder involvement	Does the guidance producer have a policy in place and adhered to that means it includes:		
	2.1 Individuals from all relevant stakeholder groups, including patient groups, in developing guidance	The guideline methodology ² involves relevant professionals and parent representatives in reviewing the existing guideline, generating key questions, assessing evidence and developing statements for Delphi consensus, through which the recommendations were agreed. Participants are detailed in the guideline ² , demonstrating the involvement of relevant professionals and parent representatives.	Criterion met
	2.2 Patient and service user representatives and seeks patient views and preferences in developing guidance	The guideline methodology ² involves parent representatives in reviewing the existing guideline, generating key questions, reviewing evidence and developing statements for Delphi consensus. The guideline ² provides details of the parent representatives.	Criterion met
	2.3 Representative intended users in developing guidance.	The guideline methodology ² includes a wide variety of target users throughout development of the guideline, with details provided in the guideline.	Criterion met
	Does the guidance producer have a clear policy in place that:		

Criterion	Evidence for meeting the criterion	Accreditation decision	
Rigour of development	3.1 Requires the guidance producer to use systematic methods to search for evidence and provide details of the search strategy	The style guide ¹ states that the process for the systematic review and the search dates should be included within the guideline. The methodology section of the guideline ² describes the systematic methods used including search terms, dates and databases. The guideline ² provides an overview of the search results and the studies meeting the inclusion criteria.	Criterion met
	3.2 Requires the guidance producers to state the criteria and reasons for inclusion or exclusion of evidence identified by the evidence review	The guideline methodology ² defines inclusion criteria such as study types and the number of study participants. It states that there was no exclusion on the basis of language and that non-English language papers were translated, which is a notable strength of the process ² . The guideline ² states the number of studies included and excluded at each stage and provides details of all the studies used. A detailed account of the Delphi consensus process is also provided, including whether statements were excluded ² .	Criterion met
	3.3 Describes the strengths and limitations of the body of evidence and acknowledges any areas of uncertainty	The style guide ¹ states that recommendations should be accompanied by a level of evidence according to the Scottish Intercollegiate Guidelines Network (SIGN) system, and any areas of uncertainty should be discussed. This can be seen in the guideline ² along with the level of consensus achieved in the Delphi process for each statement. The guideline ² includes a section on the strengths and limitations of the methods and the evidence base overall.	Criterion met

Criterion	Evidence for meeting the criterion	Accreditation decision
3.4 Describes the method used to arrive at recommendations (for example, a voting system or formal consensus techniques like Delphi consensus)	The style guide ¹ states that the methodology used to revise the guideline should be included in the guideline, which includes the Delphi consensus process. The guideline methodology ² provides a detailed account of the multidisciplinary workshop and the Delphi consensus process that were used to develop recommendations.	Criterion met
3.5 Requires the guidance producers to consider the health benefits against the side effects and risks in formulating recommendations	The guideline methodology ² uses a grading system for recommendations that explicitly includes consideration of their relative benefits and risks. The guideline ² uses the grading system, demonstrating consideration of these issues. There is also discussion of the risks of delayed diagnosis, and different risk factors for developing brain tumours ² .	Criterion met
3.6 Describes the processes of external peer review	The guideline methodology ² includes review by the Royal College of Paediatrics and Child Health (RCPCH), a range of external stakeholder organisations and peer review prior to journal publication. At the time of assessment the guideline had been reviewed by the RCPCH.	Criterion met
3.7 Describes the process of updating guidance and maintaining and improving guidance quality	The guideline methodology ² states that the guideline is reviewed every 5 years, including a systematic review and meta-analysis, a multidisciplinary workshop and Delphi consensus. Instructions are provided for unscheduled review in the event of important new evidence, to determine if an urgent update is required ² . The current version of the guideline ² is an update of the previous version.	Criterion met

Criterion	Evidence for meeting the criterion		Accreditation decision
Clarity and presentation	Does the guidance producer ensure that:		
	4.1 Recommendations are specific, unambiguous and clearly identifiable	The style guide ¹ states that the guideline should provide clear recommendations in a quick reference format, full guideline format and a series of age-specific symptom cards for parents and young people. It states how these should be presented, to ensure they are clearly written and easily identifiable ¹ . Examination of the full guideline ² including the quick reference guide and the age-specific symptom cards confirms that the recommendations are specific, unambiguous and clearly identifiable.	Criterion met
	4.2 Different options for the management of the condition or options for intervention are clearly presented	The scope of the guideline includes the management of the diagnostic process, but not management of the condition ² . The style guide ¹ states that the management process should be clearly described. Examination of the guideline ² shows that any options are clearly stated where applicable, for example different imaging modalities.	Criterion met
	4.3 The date of search, the date of publication or last update and the proposed date for review are clearly stated	The style guide ¹ states that the guideline should clearly state the date of search, the date of publication and the proposed date for review. The guideline ² provides the date of current review (as it has not been published yet), next review and the dates of search.	Criterion met

Criterion	Evidence for meeting the criterion	Accreditation decision	
4.4	The content of the guidance is suitable for the specified target audience. If patients or service users are part of this audience, the language should be appropriate.	The style guide ¹ states how recommendations and other important information should be presented and worded, including in the age-specific symptom cards aimed at lay people. The content and format of the guideline ² , including a quick reference guide, are suitable for the target audience of healthcare professionals. The content and language of the age-specific symptom cards ² are suitable for lay people.	Criterion met
Applicability	Does the guidance producer routinely consider:		
5.1	Publishing support tools to aid implementation of guidance	The style guide ¹ states that both a quick reference guide and age-specific symptom cards should be produced. The guideline ² includes a quick reference summary and age-specific symptom cards.	Criterion met
5.2	Discussion of potential organisational and financial barriers in applying its recommendations	The guideline methodology ² does not explicitly require a discussion of organisational or financial barriers, however examination of the guideline ² shows that the lack of availability of some imaging modalities is discussed, with alternatives suggested.	Criterion met
5.3	Review criteria for monitoring and/or audit purposes within each product.	There is a process ² to monitor the delay between symptom onset and diagnosis, which is the key measure the guideline aims to reduce. Results to date ² demonstrate that this delay has decreased substantially since the first edition of the guideline.	Criterion met
	Does the guidance producer:		

Criterion	Evidence for meeting the criterion	Accreditation decision	
Editorial independence	6.1 Ensure editorial independence from the funding body	The guideline methodology ² is clear how guideline development was funded. Editorial independence is supported by the inclusion of a wide range of stakeholders and the use of the Delphi consensus technique that minimises undue influence ² . Examination of the guideline ² confirms that the process was followed and that none of the guideline developers were affiliated with the specific funding sources.	Criterion met
	6.2 Demonstrate transparency about the funding mechanisms for its guidance	The guideline methodology ² states that guideline development was funded by a Big Lottery Fund grant for the first edition, and an NHS Innovation Award for the second edition.	Criterion met
	6.3 Record and state any potential conflicts of interest of individuals involved in developing the recommendations	The guideline methodology ² defines categories of interest and what might constitute a conflict. It provides options to manage interests, including simple declaration and recusal ² . It states that the Chair cannot have any conflicts and that most of the guideline group should not have any conflicts ² . Declarations are provided in the guideline ² , although transparency could be improved around the decisions and actions taken in some cases.	Criterion met
	6.4 Take account of any potential for bias in the conclusions or recommendations of the guidance	The guideline methodology ² is systematic and inclusive of all relevant stakeholders, whilst ensuring editorial independence. The funding source is transparent and all those directly involved have to declare any interests ² . The use of the Delphi consensus process ² helps to mitigate any risk of bias.	Criterion met

Criterion	Evidence for meeting the criterion	Accreditation decision
	<p>Documents referenced above:</p> <ol style="list-style-type: none"> 1 How to revise the Brain Tumour Diagnosis guideline: A Style guide (2016) 2 The brain pathways guideline (2016) – includes methodology sections and support tools 	

Appendix B: Bibliography

Appendix B lists the additional information taken into account in the analysis and considered by the committee.

Document name	Description	Location
Accreditation application form CBTRC Brain tumour diagnosis	Accreditation application form	Supplied
Appendix 7 MDT COI	Declarations of interest	Supplied
Appendix 8 Delphi COI	Declarations of interest	Supplied
Brain Pathways guidelines v2 RCPCH	Guideline	Supplied
Guidance producer feedback_CBTRC_1.0 to NICE	Guidance producer feedback form	Supplied
Style guide	Process document covering format of guidance	Supplied

Appendix C: NICE Accreditation Advisory Committee, external advisers and NICE Accreditation team

NICE Accreditation Advisory Committee

The NICE Accreditation Advisory Committee operates as a standing advisory committee of the Board of the National Institute for Health and Care Excellence (NICE). The Committee provides advice to NICE on a framework for accrediting sources of evidence that should be recognised as trusted sources of information for the NHS. The Chair of the Committee is appointed by the NICE Board and the meetings are conducted by the chair or in his/her absence the vice chair. The current Chair is Martin Underwood. A full list of the Accreditation Advisory Committee membership is available on the [NICE website](#). Members are appointed for a period of 3 years. This may be extended by mutual agreement for a further 3 years, up to a maximum term of office of 10 years.

The decisions of the Committee are arrived at by a consensus of the members present. The quorum is set at 50% of committee membership. The Committee submits its recommendations to the NICE Publications executive which acts under delegated powers of the NICE Board in considering and approving its recommendations.

Committee members are asked to declare any interests in the guidance producer to be accredited. If it is considered that there is a conflict of interest, the member(s) is excluded from participating further in the discussions. Committee members who took part in the discussions for this accreditation decision are listed below.

Title	Name	Surname	Role	Organisation
Dr	Adrian	Brown	Principal Screening Advisor (formerly)	Public Health England (formerly)
Mr	Richard	Brownhill	Independent health care improvement manager	Royal Bolton Hospitals Trust
Ms	Ailsa	Donnelly	Lay member	N/A

Ms	Joyce	Epstein	Lay Member	N/A
Dr	Elvira	Garcia	Consultant in Public Health Medicine - Health Protection Lead	NHS Ayrshire & Arran
Mrs	Diana	Gordon	Company Director	DRG Consultants
Ms	Barbara	Graham	Service Manager	Health Improvement Team, NHS National Services Scotland
Ms	Angela	Green	Lead clinical research therapist	Hull and East Yorkshire Hospitals NHS Trust
Dr	Steve	Hajioff	Director of Public Health	Hillingdon Borough Council
Dr	Anthony	Larkin	General Practitioner	The Alexandra Practice
Prof	Donal	O'Donoghue	Consultant Renal Physician	Salford Royal NHS Foundation Trust
Dr	Mahendra	Patel	Principal Enterprise Fellow (Senior Academic Pharmacist)	University of Huddersfield
Ms	Mandy	Sainty	Research and Development Manager	College of Occupational Therapists
Mr	Duncan	Service	Evidence Manager	Scottish Intercollegiate Guidelines Network

Dr	Sara	Twaddle	Director of Evidence	Healthcare Improvement Scotland
Prof	Martin	Underwood	Professor of Primary Care Research, Director of Warwick Clinical Trials Unit	The University of Warwick
Ms	Ruth	Wakeman	Assistant Director of Professional Development and Support	Royal Pharmaceutical Society

External Advisers for this accreditation application

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NICE Accreditation team for this accreditation application

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