



Clinical Practice Guideline

for the Management of Communication and Swallowing in Children Diagnosed with Childhood Brain Tumour or Leukaemia


Administrative & Technical Report





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Publication Approval



Australian Government
National Health and Medical Research Council

The guideline recommendations outlined in the Clinical Practice Guideline were approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) on 23 November, 2020, under Section 14A of the National Health and Medical Research Council Act 1992. In approving the guideline recommendations, NHMRC considers that they meet the NHMRC standard for clinical practice guidelines. This approval is valid for a period of 5 years. NHMRC is satisfied that the guideline recommendations are systematically derived, based on the identification and synthesis of the best available scientific evidence, and developed for health professionals practising in an Australian health care setting. This publication reflects the views of the authors and not necessarily the views of the Australian Government.

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Organisations Responsible

The University of Sydney is responsible for the development and publication of this guideline. Affiliation organisations of all Steering Committee members and authors are also acknowledged as partner organisations. These include Murdoch Children's Research Institute (MCRI); University of Melbourne; Cancer Centre for

Children at The Children's Hospital at Westmead (CHW), Kids Rehab Department at CHW; Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital, Randwick; University of New South Wales; Vrije Universiteit Brussel (VUB); and Université Libre de Bruxelles (ULB).

Guideline Development Committee

Team members

The Guideline Development Committee comprised a Lead Development Team, a Steering Committee (panel of experts) and a Health Professional and Consumer Group. The Guideline Development Committee are depicted in Figure 1.

Declarations of interests

All members of the Guideline Development Committee are shown in Table 1. They were each provided with information about potential conflicts of interest based on the NHMRC Guidelines for Guidelines online handbook (<https://www.nhmrc.gov.au/guidelinesforguidelines>). All

Figure 1
Guideline Development Committee



CBTL = Childhood brain tumour or leukaemia



Committee members were asked to identify any potential organisational or financial conflicts of interest via an electronic form. Declarations were noted from two (2) team members (Professor Claire Wakefield & Professor Angela Morgan), however, neither of these declarations were deemed to be a potential conflict of interest (see Table 1).

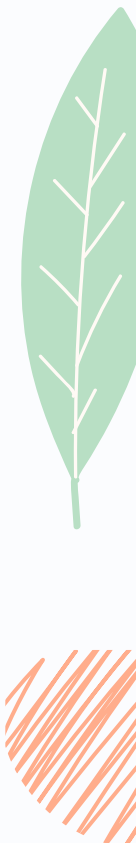
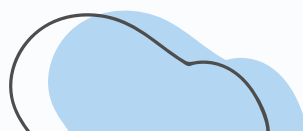
Consumer involvement

Consumers were actively recruited to participate in guideline development. Consumers were defined as both adult survivors of CBTL and parents/carers of children diagnosed with CBTL. Consumer participation was sought via email correspondence with cancer organisations: Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG) Consumer Group, RedKite, Canteen, Cancer Council and the Childhood Cancer Association. This resulted in three consumer members of the Guideline Development Committee, all mothers of children diagnosed with CBTL. One member, Ms Maria Messina served as a member of the Steering Committee. She is the mother of a child diagnosed with leukaemia. She was involved in providing her perspectives on the guideline recommendations through the GRADE Evidence to Decision (EtD) frameworks and provided feedback about the final guideline. Two consumers, Ms Marion Corbett and Ms Tracey Power provided input as members of the Health Professional and Consumer Group by completing

the survey. They are both mothers whose children were diagnosed with brain tumour. Consumers were supported via phone and email contact as required from the Chair and/or Project Co-ordinator. An information pack with Plain English terminology definitions and information was also provided to consumers to support their participation.

Aboriginal and Torres Strait Islander and culturally and linguistically diverse (CALD) community involvement

The Guideline Development Committee membership comprised one member who is an Aboriginal and Torres Strait Islander person as well as numerous CALD members. These members were recruited via the standard recruitment processes used to recruit the Health Professional and Consumer Group and Steering Committee (e.g. invitation by Chair, advertising via national associations, invites via consumer organisations). Through these processes, a total of 38% of the Guideline Development Committee chose to identify as either an Aboriginal and Torres Strait Islander person or member of a CALD group. As per all members of the Committee, Aboriginal and Torres Strait Islander and CALD members were supported via phone and email contact as required from the Chair and/or Project Co-ordinator as well as provision of an information pack with plain English terminology definitions and

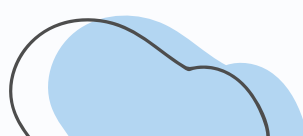


Information.

Guideline Development Committee members and declarations of interest

Name and Organisation	Role in Guideline	Declarations of Interest
Dr Kimberley Docking <i>The University of Sydney</i>	Chair	None to declare
Dr Rosemary Hodges <i>The University of Sydney</i>	Project Co-ordinator	None to declare
Dr Lani Campbell <i>The University of Sydney</i>	Research and Evidence Consultant	None to declare
Ms Sara Chami <i>The University of Sydney</i>	Research Assistant	None to declare
Ms Stefani Ribeiro Knijnik <i>The University of Sydney</i>	Research Affiliate	None to declare
Ms Emma Campbell <i>The University of Sydney; Western Sydney Local Health District</i>	Research Assistant	None to declare
Professor Angela Morgan <i>Murdoch Children's Research Institute; University of Melbourne</i>	Steering Committee	Royalties from book (Ward E and Morgan A. 2008. Dysphagia Post Trauma. Plural publishing) (2008-current)
Professor Claire Wakefield <i>School of Women's and Children's Health, UNSW Medicine, UNSW Sydney; Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital</i>	Steering Committee	Recipient of a Career Development Fellowship from the National Health and Medical Research Council of Australia (APP1143767) (2019-2021)

<p>Professor Philippe Paquier</p> <p><i>Vrije Universiteit Brussel (VUB) & Université Libre de Bruxelles (ULB)</i></p>	Steering Committee	None to declare
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<p>Dr Mary-Clare Waugh</p> <p><i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network; The University of Sydney Medical School</i></p>	Steering Committee	None to declare
<p>Ms Maria Messina</p> <p><i>Consumer</i></p>	Steering Committee	None to declare
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<p>Ms Hayley Coulson</p> <p><i>Queensland Children's Hospital</i></p>	Health Professional and Consumer Group	None to declare
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<p>Ms Suzi Drevensek <i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network</i></p>	<p>Health Professional and Consumer Group</p>	<p>None to declare</p>
<p>Dr Robyn Stargatt <i>La Trobe University</i></p>	<p>Health Professional and Consumer Group</p>	<p>None to declare</p>
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Marion Corbett <i>Consumer</i>	Health Professional and Consumer Group	None to declare
Tracey Power <i>Consumer</i>	Health Professional and Consumer Group	None to declare

Guideline Development Process

Guideline development: Evidence sources

The two main recommendations in this guideline as well as the key practice points have been informed by three sources of evidence as detailed below and depicted in Figure 2.

1. Systematic review of the literature: GRADE Certainty of Evidence ratings and narrative synthesis methods
2. Input from a Steering Committee comprised of research/clinical experts and a consumer via the GRADE EtD framework
3. Input of a Health Professional and Consumer Group via a survey

Public consultation

Direct invitations to provide comment on the draft guideline were sent to 45 relevant professional and consumer organisations (see Appendix A for list of invited organisations) and their members. The guideline was released for public consultation on The University of Sydney website on July 13, 2020. The draft guideline was also provided to the Director-General, Chief

Executive, and Secretary of each State, Territory and Commonwealth Departments of Health in Australia. The public consultation submissions summary is available upon request.

Formal endorsement

The Guideline Development Committee sought NHMRC approval of the guideline under Section 14A of the National Health and Medical Research Council Act 1992. No further formal endorsements were sought by the developers. However, several organisations provided a letter of support for the Guideline during the public consultation phase. Organisations communicating support included:

- American Speech-Language-Hearing Association (ASHA)
- Brain Tumour Alliance Australia (BTAA)
- Childhood Cancer Australia
- WA Health
- Department of Health, Northern Territory Government
- Queensland Health

Figure 2

Sources of evidence that were used to inform recommendations in this guideline



GRADE = Grading of Recommendations, Assessment, Development and Evaluation
EtD = Evidence-to-Decision

Independent expert and methods review

Anonymous, independent review of the guideline using the Agree II instrument¹ was facilitated by NHMRC and

completed following public consultation July-August 2020. The Chair provided the names of 16 potential international and national independent expert reviewers to NHMRC. Methods review was commissioned by NHMRC and completed in September 2020.

Systematic Literature Review

A systematic review of the literature on communication and swallowing outcomes associated with CBTL was completed as one source of evidence to inform the guideline as shown in Figure 3. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses [PRISMA] guidelines² was used to guide systematic review reporting. This systematic review has also been prepared in the form of a journal article for submission to a peer-reviewed journal in the field (Hodges et al³). The methods and results of the systematic review are detailed below.

Systematic review methods

Clinical questions

To guide the evidence review for this guideline, two clinical questions were developed. The questions were developed by the Chair and Project Co-ordinator with opportunities for feedback from the Steering Committee. The questions are consistent with the PICOTS (population, intervention, comparison, outcome, timing,

setting) format.⁴ The PICOTS typology is suited to review questions that seek to examine the most likely course/outcome for individuals with a certain health condition.⁴ The clinical questions are shown in Box A.

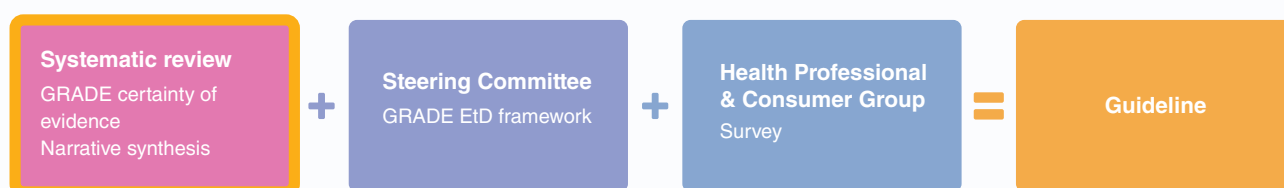
Criteria for considering studies in this review (inclusion criteria)

The PICOTS format was used to guide the development of the search criteria given that both clinical questions were in this format. In keeping with guidelines regarding the search of literature that is likely to contain many non-randomised studies, a broad search strategy was implemented.^{4,5}

The population concept in the search strategy was purposefully broad (i.e., brain cancer or leukaemia AND child) so as to capture studies across all potential population subgroups. In keeping with NHMRC requirements, a search strategy was trialled in which Aboriginal and Torres Strait Islander search terms were included in the population search strategy (i.e., brain

Figure 3

One source of evidence to inform guidelines: Systematic review



GRADE = Grading of Recommendations, Assessment, Development and Evaluation

EtD = Evidence to Decision

cancer or leukaemia AND child AND Aboriginal and Torres Strait Islander). This resulted in 0 studies being retrieved and thus the decision was made to maintain the broad population search strategy. Issues relevant to possible population subgroups including Aboriginal and Torres Strait Islander peoples are identified in the guideline and the Dissemination and Implementation Plan.

Types of studies

Primary research (excluding case reports) published between January 1998 and August 2019^a and available in the English language.^b

Types of participants

Children aged 0-16 years diagnosed with CBTL (studies that involved a mixed adult/child sample were included if the mean age of the participants was ≤16 years old).

Types of prognostic factors

Any type of childhood brain tumour or leukaemia.

Types of outcome measures

Speech, language^c or swallowing outcome measures.

Timing and setting

Any timing across oncology phases: at diagnosis prior to cancer treatment, during the oncology treatment phase, during the oncology follow-up phase, during the survivorship phase. Both inpatient and outpatient settings were included.

Search methods for identification of studies (search strategy)

Database searches

The following databases were searched:

- Medline (via OvidSP) 1946- 21 August 2019
- CINAHL (via EbscoHost) 1982-21 August 2019
- Embase (via OvidSP) 1947-21 August 2019
- Web of Science (via Clarivate Analytics)

The search strategy used for each database is shown in Appendix B.

Box A

Clinical questions

Communication Outcomes

What are the communication outcomes associated with childhood brain tumour or leukaemia?*

Swallowing Outcomes

What are the swallowing outcomes associated with childhood brain tumour or leukaemia?*

*PICOTS format – Population (P): Children with aged 1-16 with brain tumour or leukaemia; Intervention (I) – Any; Comparison (C) – Any; Outcome (O) – Communication/Swallowing; Timing (T) – At diagnosis prior to cancer treatment, during the oncology treatment phase, during the oncology follow-up phase, during the survivorship phase; Setting (S) – Both inpatient and outpatient settings.

^aIn initial search strategy, a wider date range (1988 – 2019) was used. However, at the full-text assessment, this was refined to 1998 – 2019

^bIn initial search strategy, English language was not selected as a filter. However, this was applied at the full-text assessment stage

^cTo be included, studies needed to use sufficiently detailed assessment of language skills, beyond one subtest of a larger cognitive or neuropsychological battery.

Grey literature search

A grey literature search was also completed via the following methods:

- Search of databases Scopus, Trove and Proquest Central using keywords for conference proceedings, books or thesis that may contain relevant empirical research
- Search of Google using select keywords
- Key authors search and consulting with key authors in the field.

Data collection and analysis

Selection of studies

Title and abstract scanning followed by full-text assessment was completed by the Project Co-ordinator and Chair using the inclusion criteria. Consensus was reached for any articles requiring further scrutiny to ensure adherence to eligibility criteria. Covidence software (<https://www.covidence.org/home>) was used to facilitate this process.

Data extraction and management

Data from all included studies was extracted into spreadsheets that were piloted and revised as required for each outcome (communication and swallowing). For communication, study outcomes fell into 3 distinct categories: speech, language, and speech+language. Therefore, data extraction was further subdivided across these categories.

A two-phase data extraction process was used. First, details including citation, funding sources, participant details, overall aim and findings of the studies were extracted by two research assistants. During the second phase, the Project Co-ordinator extracted study design (prospective or retrospective, and observational and/or analytical), outcome measure/s, timing, setting and detailed key findings. Key findings focused on the nature of communication and/or swallowing difficulties and informed the narrative summaries for communication and swallowing. The Chair reviewed the data extraction

spreadsheets and any disagreements were discussed between Project Co-ordinator and Chair and agreement obtained.

Individual quality assessment and quality assessment of the body of evidence (GRADE certainty of evidence)

Individual studies were dually assessed by two research assistants using the appropriate Joanna Briggs critical appraisal tools (https://joannabriggs.org/ebp/critical_appraisal_tools).^{6,7} Each study was given a numerical score to reflect the impact on risk of bias.

The GRADE certainty of evidence process (<https://www.gradeworkinggroup.org/>) was used to assess the quality of the body of evidence for each outcome (communication [subdivided into speech, language and speech+language] and swallowing). The GRADE certainty of evidence process included assessment of the following five parameters: risk of bias, inconsistency, imprecision, indirectness and publication bias.⁸ Certainty of evidence ratings for each parameter per outcome were made by the Chair and Project Co-ordinator, with input from the Research and Evidence Consultant where needed. For each outcome, an overall GRADE certainty of evidence rating was given.

Data synthesis

Due to heterogeneity of studies in terms of design and outcome measures, narrative synthesis, not meta-analysis, was conducted. Narrative synthesis was guided by the SWiM guidelines designed for the reporting of methods and results in narrative systematic reviews.⁹ For each outcome (communication [further subdivided into speech, language, speech+language] and swallowing), narrative summaries were guided by pre-defined items as shown in Box B.

Box B

Systematic review narrative summary items

Study design

A summary of the types of study designs included

Participant number and cancer type

A count of total number of CBTL participants and a summary of their ages. Identification of the number of studies focused on brain tumour, leukaemia or both

Outcome measure

A descriptive summary of the types of outcome measures used

Timing

A count of the timing of assessment using pre-defined author-developed oncology phases (at diagnosis/prior to cancer treatment, oncology treatment phase, oncology follow-up phase [<5 years since cancer treatment], survivorship phase [5+ years since cancer treatment])

Setting

A count of the setting in which assessment took place using pre-defined author-developed binary categories of inpatient (hospital) or outpatient (any setting outside of hospital such as outpatient clinic, home, school, university clinic). Setting was not always explicitly stated in the studies but was determined as inpatient or outpatient setting based on timing

Key findings

A descriptive summary of the nature of communication/swallowing difficulties

Adapted from Hodges et al³

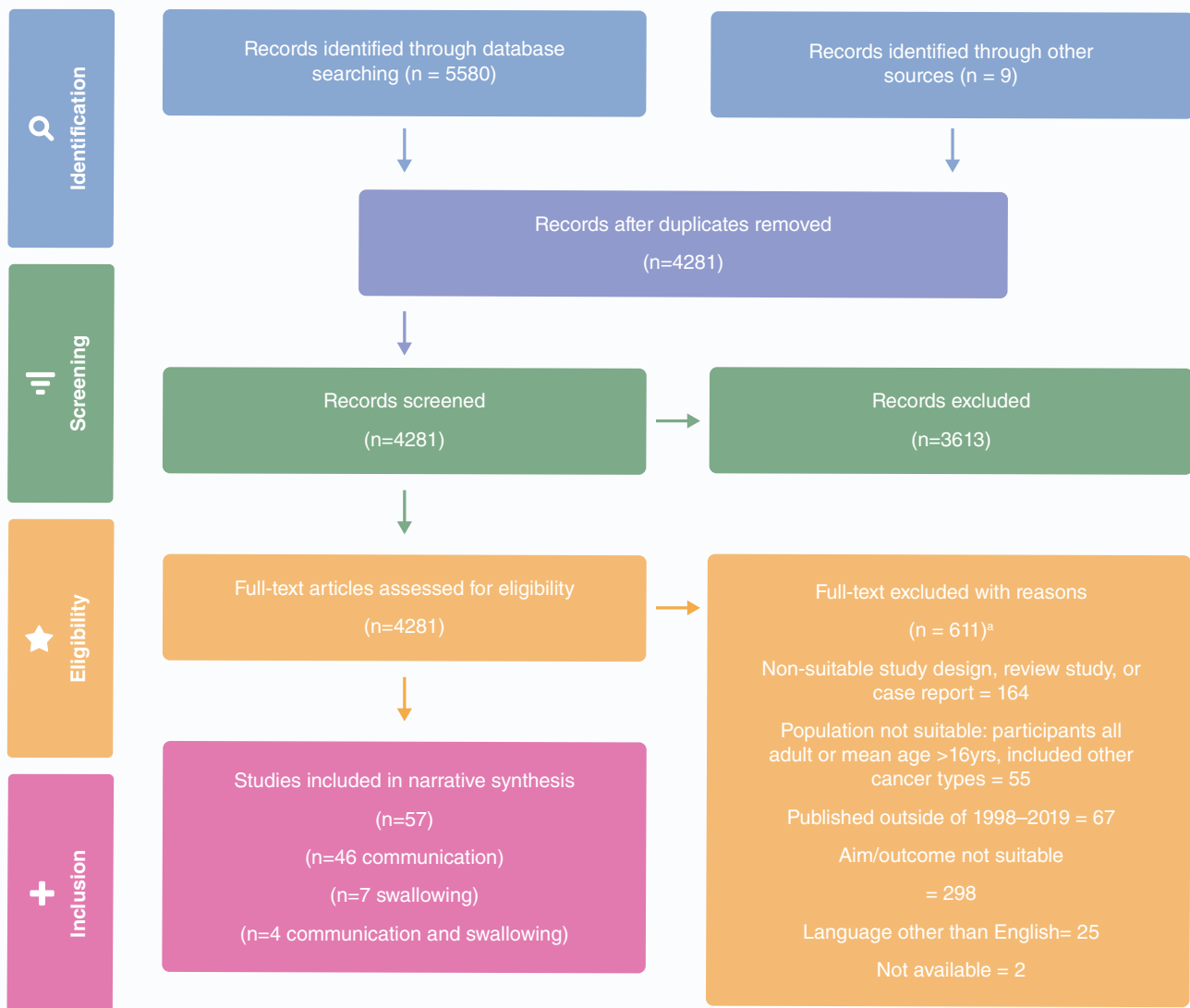
Systematic review results

Study selection

Following the removal of duplicates, 4281 papers were retrieved. After title and abstract scanning, 668 were included for full-text assessment based on inclusion criteria. The final number of included studies was 57 (50 included examination of communication outcomes and 11 included examination of swallowing outcomes

[Note: four articles included both communication and swallowing outcomes]). The PRISMA flowchart detailing the selection process is shown in Figure 4. All included studies can be seen in Tables 2 and 3. Studies excluded at the full-text level can be requested from the authors of the guideline.

Figure 4
Study selection process flow chart (Hodges et al³)



^aThree additional exclusion criteria were applied at full-text assessment: case reports, studies published in a language other than English and studies published prior to 1998.

Characteristics of included studies

Study design

Across all 57 included studies, there were 36 descriptive studies, 14 which included both descriptive and analytic components and seven that were analytic. The study designs specific to outcome are shown in Figure 5. The study designs of each included study are shown in Tables 2 and 3.

Types of participants

There were 2308 participants included across all studies, all of whom had been diagnosed with brain tumour or leukaemia. Sample size ranged from four to 450, although sample sizes were generally relatively small across most studies (M = 40). The age range of included participants was wide from <1-year-old to beyond 16 years old. As per inclusion criteria, studies that involved

Figure 5

Study designs for included studies by outcome

 Communication	<ul style="list-style-type: none">• 29 descriptive studies, 14 descriptive and analytic, 7 analytic• 39 prospective, 10 retrospective, 1 retrospective+prospective
 Swallowing	<ul style="list-style-type: none">• 11 descriptive studies• 5 prospective, 5 retrospective, 1 retrospective+prospective

a mixed adult/child sample were included if the mean age of the participants was ≤ 16 years old. The number and age range of participants specific to outcome are shown in Figure 6. The age range of participants for each study are included in Tables 2 and 3.

Types of prognostic factors

While all included participants had been diagnosed with either brain tumour or leukaemia, there were noted to be more studies on children with brain tumour, specifically posterior fossa brain tumour. The prognostic factors specific to outcome are shown in Figure 7. The diagnoses of children included in each study are shown in Tables 2 and 3.

Types of outcome measures

Outcome measures were varied across the literature as demonstrated in Tables 2 and 3. For communication,

these included rating the presence/absence of a specific difficulty, observed difficulties, criterion-referenced tools and checklists, acoustic measures and standardised assessment tools. For swallowing, these included chart reviews, presence/absence of swallowing difficulty, observation of difficulties, criterion-referenced tools, patient-reported difficulties and videofluoroscopy.

Timing and setting

Communication and swallowing outcomes were studied at various points in time from cancer diagnosis through to survivorship and across both inpatient (e.g. hospital) and outpatient (e.g. school, university clinic, home) settings as highlighted in Tables 2 and 3. Some studies included assessment at one point in time, while others included assessments across multiple points in time. To conceptualise the timing and setting of assessment, the Project Co-ordinator and Chair developed the Timing

Figure 6

Number and types of participants in included studies by outcome



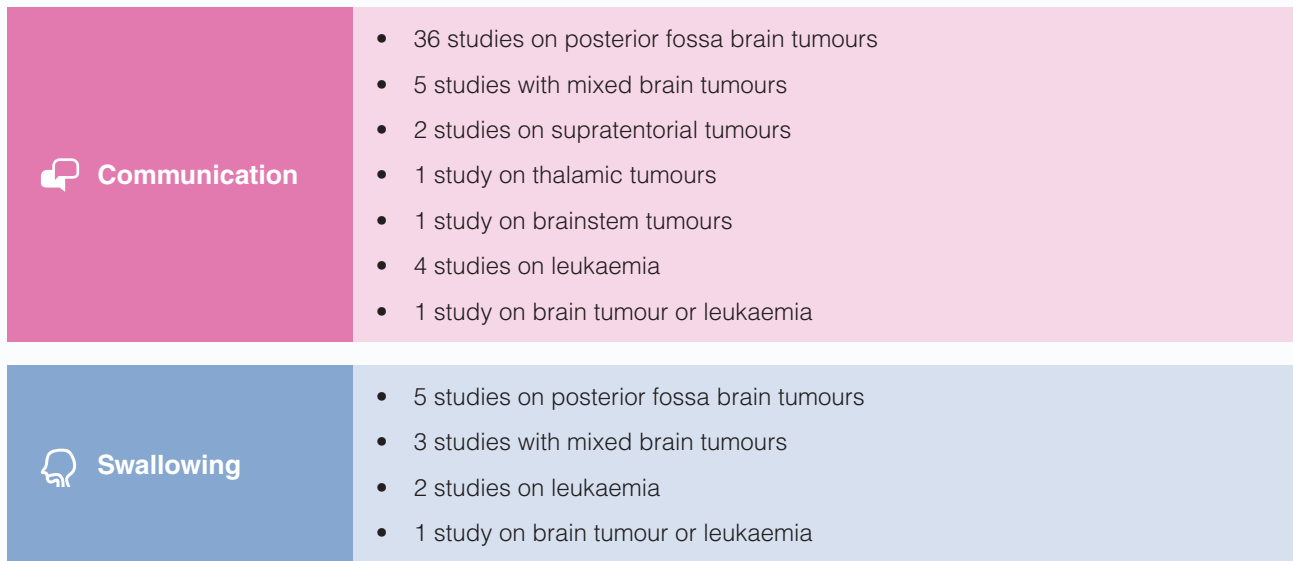
 Communication	<ul style="list-style-type: none">• Total N: 1875 (277 language, 511 speech, 1087 speech+language)• Age range: <1-year-old - 24-years-old (mean age ≤ 16 years)• All diagnosed with CBTL
 Swallowing	<ul style="list-style-type: none">• Total N: 739• Age range: <1-year-old – 22-years-old (mean age ≤ 16 years)• All diagnosed with CBTL

Figure 7

Prognostic factors (cancer diagnoses) of participants in included studies by outcome



and Setting Framework as shown in Figure 8. As seen in the figure, communication outcomes have been studied across all time points. Specifically, speech outcomes have most often been examined at diagnosis/pre-treatment or during oncology treatment, while language outcomes have most often been examined after cancer treatment during oncology follow-up and/or survivorship

phases. Swallowing outcomes have primarily been studied acutely at diagnosis and/or during oncology treatment. Short-term follow-up of swallowing into the oncology follow-up phase has been studied to some extent, but only one study considered swallowing outcomes in the survivorship phase.

Figure 8

Framework of timing and setting: Communication and swallowing outcomes

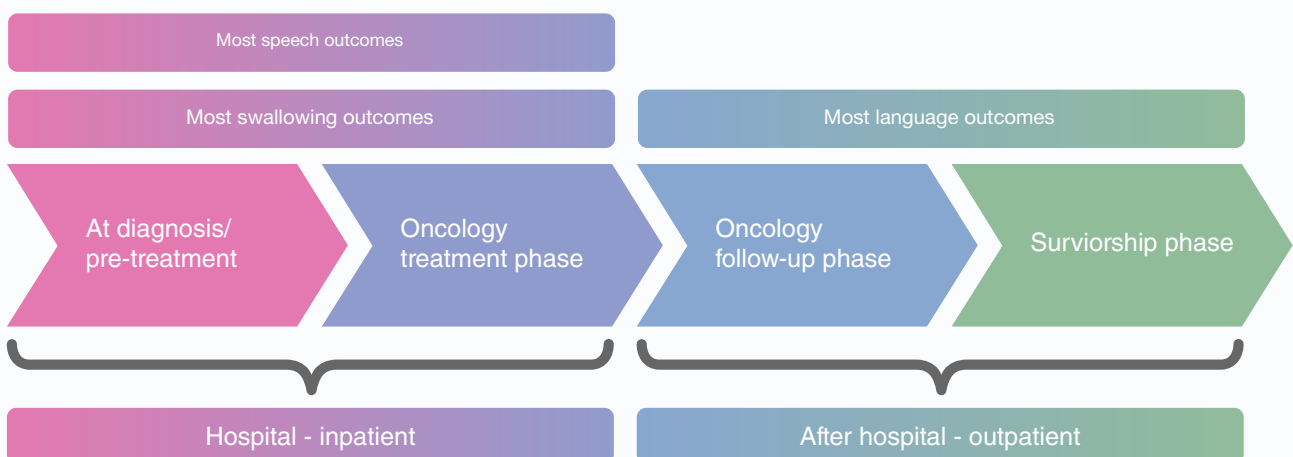


Table 2

Characteristics of included studies: Communication (speech, language, speech+language) (adapted from Hodges et al³)

Study	Study design	No of participants	Age (range) & cancer type	Outcome measure	Timing	Setting	Key findings
SPEECH							
Beckwitt et al, 2012¹⁰	Descriptive Prospective	22	14 months - 17 yrs BT: posterior fossa	Presence of PFS	Dx/PT OTP	Inpatient	91% of cases diagnosed with PFS post-surgery. The same symptoms were not seen in every patient, and time in which they improved varied
Brannon Morris et al, 2009¹¹	Descriptive Prospective	42	8 months - 22.7 yrs BT: posterior fossa	Observational rating scale	OTP OFuP SP	Inpatient Outpatient	19% of cases diagnosed with dysarthria post-surgery, increasing to 31% at 3-year follow-up, and reported in 14% at 5-year follow-up
Catsman-Berrevoets et al, 1999¹²	Descriptive Prospective	42	2 - 17 yrs BT: posterior fossa	Spontaneous sample, repetition of words/sentences, observational rating scales, oral-musculature assessment	Dx/PT OTP OFuP	Inpatient Outpatient	29% of cases developed mutism and dysarthria post-surgery, none exhibited symptoms pre-surgery. Mutism duration was noted to be from one day to 5 months
Cornwell et al, 2005¹³	Descriptive Prospective	6 (+6 comparison)	6.5 - 13.3 yrs BT: posterior fossa	Standardised assessment, perceptual and physiological analyses of speech sample	OFuP	Outpatient	50% of cases exhibited dysarthric speech. All cases with dysarthria had impairments in prosody, articulation, and phonation
Cornwell et al, 2003¹⁴	Descriptive-analytic Prospective	21 (+21 controls)	6 - 14.6 yrs BT: posterior fossa	Standardised assessment, perceptual analyses of speech sample, intelligibility scales, oral-musculature assessment	OFuP SP	Outpatient	All cases exhibited mild dysarthria up to 8 years post-cancer treatment, notably in prosody, phonation, and articulation. They displayed imprecise consonants, hoarseness, decreased pitch variation and reduced intelligibility relative to controls. Oro-motor deficits included lip, tongue and laryngeal dysfunction, particularly in timing and coordination of movements

Cornwell et al, 2004 ¹⁴	Descriptive-analytic Prospective	9 (+21 controls)	6.5 - 14.5 yrs BT: posterior fossa	Perceptual judgement of dysarthria, perceptual and acoustic evaluation of voice	OFuP SP	Outpatient	100% of cases had dysarthria ranging from mild to moderate. 78% of cases had impaired vocal quality including roughness, instability, breathiness and asynchronicity while in the control group, all cases had normal vocal quality
De Smet et al, 2012 ¹⁵	Descriptive Retrospective and prospective	24	3.1 - 19.9 yrs BT: posterior fossa	Retrospective chart review of post-surgery features and perceptual speech sample analysis	OFuP SP	Outpatient	50% of cases experienced post-surgery mutism with duration ranging from 7 days up to 5.3 months. All cases who experienced post-surgery mutism subsequently presented with dysarthria at the time of assessment. 41% of cases without mutism also exhibited some speech deficits. Speech deficits characterised by distorted vowels, slow speech rate, voice tremor and monopitch
Huber et al, 2007 ¹⁶	Analytic Prospective	21 (+20 controls)	Age range not reported all child participants <18yrs BT: posterior fossa	Dysarthria rating scale, fluency coding, speech rate	SP	Outpatient	Compared to control group, the BT group showed evidence of neuromotor speech deficits (ataxic dysarthria, dysfluency) more than 5 years after diagnosis
Korah et al, 2010 ¹⁷	Descriptive Retrospective	63	3.3 - 24 yrs BT: posterior fossa	Diagnosis of PFS identified via review of clinical notes and CMS survey	OFuP SP	Outpatient	29% of cases diagnosed with PFS post-surgery. At a median 5-year follow-up, speech deficits were present in the majority of children who had experienced PFS. Most commonly, these were characterised by dysarthric speech and ataxia
Kotil et al, 2008 ¹⁸	Descriptive Prospective	32	3 - 13 yrs BT: posterior fossa	Presence of CM using a checklist	Dx/PT OTP OFuP	Inpatient Outpatient	No cases showed speech difficulties prior to surgery. 32% of cases developed cerebellar mutism post-surgery
Kupeli et al, 2011 ¹⁹	Descriptive Prospective	36	Range not reported, all <16 yrs BT: posterior fossa	Presence of PFS	Dx/PT OTP	Inpatient	25% of cases developed PFS post-surgery. Mutism developed within 4 days of surgery continuing for 1-14 days in all but one case (120 days in that case)

Liu et al, 2018 ²⁰	Descriptive Retrospective	89	2 - 23 yrs BT: posterior fossa	Reduced/absent speech ascertained from chart using pro-forma	OTP	Inpatient	29% of cases developed CMS post-surgery
Mei & Morgan, 2011 ²¹	Descriptive Retrospective	27	2 - 18 yrs BT: posterior fossa	Presence of mutism and dysarthria ascertained from chart	Dx/PT OTP OFuP	Inpatient Outpatient	Pre-surgery dysarthria in 15% of cases. Post-surgery dysarthria in 30% of cases. Post-surgery mutism seen in 33% of cases. In those with mutism, 75% experienced dysarthria following mutism
Morgan et al, 2011 ²²	Descriptive Prospective	13 (+26 comparison)	9.1 - 19.6 yrs BT: posterior fossa	Perceptual dysarthria checklist, oral-musculature assessment, motor speech profile	OFuP SP	Outpatient	77% of cases diagnosed with persistent dysarthria up to at least 10+ years post-surgery, affecting intelligibility or naturalness of speech. 15% of cases had mutism. Compared to the comparison cases, those diagnosed with BT had more deviant speech features, vocal deficits, slower DDK production and slower speech rate
Ozimek et al, 2004 ²³	Descriptive Prospective	14 (+10 comparison)	Range not reported. Mean age 7.5 yrs for CM group; 12.5 yrs for non-CM group BT: posterior fossa	Presence of CM; perceptual speech analysis, acoustic speech analysis	Dx/ PTOTP	Inpatient	18.5% of cases who were operated on for posterior fossa tumour were diagnosed with mutism post-surgery in this setting. The four cases with cerebellar mutism are focused on in this study. Of the four with cerebellar mutism, 50% experienced dysarthria following mutism
Richter, Schoch, Ozimek et al, 2005 ²⁴	Analytic Prospective	10 (+10 controls)	8 - 16 years BT: posterior fossa	Perceptual and acoustic speech analyses, diadochokinetic rate, sentence production	Dx/PT OTP	Inpatient	Compared to control group, the BT group showed some mild symptoms of dysarthria
Van Mourik et al, 1998 ²⁵	Descriptive Prospective	12	4 - 14 yrs BT: posterior fossa and brainstem	Perceptual speech analysis	Dx/PT OTP	Inpatient	No cases displayed dysarthria prior to cancer treatment. All cases with cerebellar posterior fossa tumour experienced cerebellar mutism post-surgery followed by dysarthria. The cases with brainstem tumour did not experience mutism but exhibited hypernasality

Wells et al, 2010 ²⁶	Descriptive Retrospective	28	Range not reported. Mean age 6.19 yrs for CMS group; 7.05 yrs for non-CMS group BT: posterior fossa	Presence/absence of CMS from chart review using a rating scale	OT	Inpatient Outpatient	39% of cases diagnosed with cerebellar mutism syndrome post-surgery
LANGUAGE							
Ait Khelifa-Gallois et al, 2015 ²⁷	Analytic Prospective	17 (+61 controls)	6.7 - 17.9 yrs BT: posterior fossa	Standardised reading assessments, clinical observation	SP	Outpatient	Compared to control group, BT group had significantly poorer reading abilities (accuracy, speed, comprehension and silent reading)
Docking et al, 2016 ²⁸	Descriptive-analytic Prospective	17 (+17 controls)	5.6 - 14.1 yrs BT: mixed	Criterion-referenced narrative assessment, analysis of macrostructure and microstructure	OFuP SP	Outpatient	Compared to control group, there was no significant differences for BT group on narrative skills (macrostructure and microstructure). At an individual level, narrative performance differences were identified between groups for both macrostructure and microstructure, with children with BT tending to perform poorer
Docking et al, 2003a ²⁹	Descriptive-analytic Prospective	6 (+6 controls)	3.10 - 14.1 yrs BT: supratentorial	Standardised language assessments	OFuP SP	Outpatient	Compared to control group, BT group had significantly poorer expressive language and total (overall) language. The groups did not differ on receptive language, vocabulary or naming. Given the very small sample, individual analysis also reported. At an individual level, 2/6 cases from the BT group displayed general language deficits

Docking et al, 2003b ³⁰	Descriptive-analytic Prospective	5 (+5 controls)	7.4 - 14.1 yrs BT: supratentorial	Standardised assessments of high-level language and phonological awareness	OFuP SP	Outpatient	Compared to control group, BT group had significantly poorer high-level language in some areas, but no significant group differences were found for phonological awareness. Given the very small sample, individual analysis also reported. At an individual level 2/5 cases from the BT group displayed high-level language difficulties while 4/5 cases showed phonological awareness difficulties
Docking et al, 2004 ³¹	Descriptive Prospective	12 (+12 controls, results not reported)	3.9 - 13.6 yrs BT: posterior fossa	Standardised language assessments, including high-level language and phonological awareness	OFuP SP	Outpatient	25% of cases had general language impairments, 60% of cases had high-level language difficulties and 50% of cases had phonological awareness difficulties
Docking et al, 2005 ³²	Descriptive-analytic Prospective	6 (+6 controls)	5.6 - 14.11 yrs BT: brainstem	Standardised language assessments, including high-level language and phonological awareness	OFuP SP	Outpatient	Compared to control group, BT group did not significantly differ on general language, high-level language or phonological awareness. Given the very small sample, individual analysis also reported. At an individual level, 1/6 cases from the BT group displayed specific high-level language deficits and 1/6 cases displayed a specific phonological awareness difficulty
Dowling et al, 2014 ³³	Descriptive-analytic Prospective	7 (+7 controls)	6.2 - 8.2 yrs Leukaemia: ALL	Standardised high-level language assessment: figurative language subtest	OFuP SP	Outpatient	Compared to control group, leukaemia group did not significantly differ on figurative language. Given the small sample size, individual analysis also reported. At the individual level, 1/7 cases from leukaemia group displayed a mild figurative language deficit
Kirschen et al, 2008 ³⁴	Analytic Prospective	12 (+12 controls)	6 - 19 yrs BT: posterior fossa	Standardised phonological processing and phonemic/verbal fluency assessments	OFuP SP	Outpatient	Compared to control group, BT group did not significantly differ on phonological processing or phonemic/verbal fluency

Lafay-Cousin et al, 2009 ³⁵	Descriptive-Analytic Retrospective	12	Range not reported. Mean age 6.87 yrs for radiation group; 6.44 yrs for none/limited radiation group BT: posterior fossa	Standardised vocabulary assessment, standardised reading/spelling assessment	OFuP SP	Outpatient	Cases with BT who had received conventional craniospinal irradiation displayed literacy deficits and had receptive vocabulary skills in the low-average range. Cases with BT who had none/limited radiotherapy had literacy and receptive vocabulary skills within normal range
Levisohn et al, 2000 ³⁶	Descriptive Retrospective	19	3.8 - 16.6 yrs BT: mixed	Standardised naming assessment and clinical observation of word-finding in language sample	OTP OFuP	Inpatient Outpatient	37% of cases met criteria for expressive language deficit. Another 21% had specific word-finding difficulties but otherwise intact expressive language
Lewis & Bohan, 2018 ³⁷	Descriptive Prospective	5	10.2 - 15.1 yrs Leukaemia: ALL	Standardised language assessments, including high-level language	SP	Outpatient	Of the five cases, 3 displayed high-level language difficulties. All had intact general language abilities, except for one case which was borderline impaired
Lewis & Murdoch, 2011 ³⁸	Descriptive-analytic Prospective	4 (+20 control)	5.1 - 14.1 yrs BT: posterior fossa	Standardised language assessments, including high-level language	SP	Outpatient	BT group did not significantly differ on language measures compared to the control group. Given the very small sample size, individual analysis also reported. At an individual level, 3/4 cases had language difficulties
Lewis & Murdoch, 2013 ³⁹	Descriptive Prospective	4	5.1 - 16.1 yrs BT: posterior fossa	Standardised language assessments, including high-level language	OFuP SP	Inpatient Outpatient	2/4 cases displayed general language difficulties across various follow-up time points, and 2/3 cases displayed difficulties with higher-level language tasks
Lewis et al, 2011 ⁴⁰	Analytic Prospective	13 (+13 controls)	4.8 - 14.8 yrs Leukaemia: ALL	Standardised language assessments, including high-level language	OFuP SP	Outpatient	Compared to control group, leukaemia group performed significantly poorer for general expressive language and figurative language. They were not significantly different on general receptive, overall language and other high-level language subtests

Lonnerblad et al, 2017 ⁴¹	Descriptive Retrospective	45	9 - 18 yrs BT: mixed	Standardised literacy assessment	OFuP SP	Outpatient	71% of cases performed significantly poorer than age-equivalent test norms for reading speed and 100% of cases for spelling. They did not perform significantly different to test norms for reading comprehension or word comprehension
Murdoch et al, 2004 ⁴²	Descriptive-analytic Prospective	12 (+12 controls)	3.9 - 13.6 yrs BT: posterior fossa	Standardised language assessments, including high-level language and phonological awareness	OFuP SP	Outpatient	Compared to control group, BT group performed significantly poorer for general language, receptive vocabulary and high-level language tasks. There was no difference between the groups for phonological awareness. On an individual level, 7/12 cases evidenced some language deficits
Palmer et al, 2014 ⁴³	Descriptive-analytic Prospective	81	4 - 21 yrs BT: posterior fossa	Standardised assessment of reading decoding	OTP	Inpatient	Reading decoding scores while receiving cancer treatment were in the average range
SPEECH + LANGUAGE							
Aarson et al, 2004 ⁴⁴	Descriptive Prospective	23	6.7 – 22.11 yrs BT: posterior fossa	Speech: checklist and observation in spontaneous sample Language: standardised grammar assessment and observation in spontaneous sample	OFuP SP	Outpatient	22% of cases had dysarthria. Speech difficulties included changes in vocal quality, articulation problems, slow speech rate, voice tremor and stress problems. 30% of cases had language difficulties including word finding problems, telegraphic speech, semantic-pragmatic difficulties and phonologic agraphia
Catsman-Berrevoets & Aarsen, 2010 ⁴⁵	Descriptive Prospective	148 with BT 41 with PFS included for further analysis	1 - 17 yrs BT: posterior fossa	Speech: checklist and observation in spontaneous sample Language: observation during neurological tests	OTP OFuP	Inpatient Outpatient	26.6% of cases diagnosed with PFS post-surgery. 88% of the PFS cases had autism. Those without autism had limited verbal output. After autism resolved, common speech problems included slow rate, short phrases, hypophonia and excess/equal stress. Observed language difficulties included word finding problems, comprehension problems and perseverations in some cases

Chieffo et al, 2014 ⁴⁶	Descriptive Prospective	20	Range not reported. All > 18 months; mean age 10.41 yrs BT: thalamic tumours	Speech: fluency, articulation and prosody observed during language assessments Language: standardised language assessments, criterion-referenced verbal fluency assessment to examine semantic and phonological access	Dx/PT	Inpatient	All cases presented with speech and language difficulties at the time of cancer diagnosis across the following areas: fluent oral output, naming, word comprehension, repetition, articulation and prosody
De Smet et al, 2009 ⁴⁷	Descriptive Prospective	8	3 - 15 yrs BT: posterior fossa	Speech: observation of mutism and dysarthric features Language: standardised language assessment, family interview	OTP OFuP	Inpatient Outpatient	50% of cases developed transient mutism post-surgery followed by dysarthric speech. 62.5% of cases displayed language difficulties including grammatical problems, word finding difficulties, decreased verbal fluency, language comprehension difficulties and telegraphic-type speech
Di Rocco et al, 2011 ⁴⁸	Descriptive Prospective	34	2 - 16 yrs BT: posterior fossa	Speech: observation of apraxia characteristics Language: standardised language assessments, mean length of utterance and criterion-referenced verbal fluency assessment tool to examine semantic and phonological access	Dx/PT OTP	Inpatient	32.3% of cases presented with pre-surgery speech and/or language difficulties. Post-surgery, 20.6% of cases developed CMS. All cases that developed CMS had displayed pre-surgery speech/language difficulties
Di Rocco et al, 2010 ⁴⁹	Descriptive Prospective	41	2 - 16 yrs BT: posterior fossa	Speech: presence of CMS Language: standardised language assessments, mean length of utterance and criterion-referenced verbal fluency assessment to examine semantic and phonological access	Dx/PT OTP	Inpatient	Pre-surgery, all cases had reduced MLU and 27% displayed language processing deficits. Post-surgery, 15% developed CMS. 22% had reduced MLU and seven of these had verbal fluency difficulties

Frank et al, 2007 ⁵⁰	Descriptive-analytic Prospective	9 (+ 11 controls)	9 - 18 yrs BT: posterior fossa	Speech: repetition of syllables and sentences, observation and rating scale for dysarthria in spontaneous sample Language: Noun/verb generation task, observation and rating scale in spontaneous sample	OTP	Inpatient	Compared to control group, BT group did not differ on naming or verb generation task. No differences between groups on repetition of syllables and sentences. Observations of spontaneous sample indicated 44% of cases presented with speech difficulties: two diagnosed as dysarthria and two displayed laboured speech
Frank et al, 2008 ⁵¹	Descriptive-analytic Prospective	8 (+ 11 controls)	9 - 18 yrs BT: posterior fossa	Speech: observations in spontaneous sample using rating scales from standardised aphasia test Language: two subtests from standardised aphasia test examining receptive language and written language, observations in spontaneous sample	OTP	Inpatient	Observations of spontaneous speech sample indicated 37.5% of cases displayed speech and/or language difficulties. Compared to control group, BT group did not differ on tests of receptive vocabulary or written language
Goncalves et al, 2008 ⁵²	Descriptive Prospective	190	1 - 20 yrs BT: Mixed	A screening process: clinical protocol and a questionnaire	OTP	Inpatient	This study examined incidence of speech-language difficulties at one institution in cases with CNS tumours receiving cancer treatment. 16% had speech difficulties (stuttering, dysarthria, articulation problems), 14% had voice problems (dysphonia) and 14% had language difficulties (reading, writing, oral language)
Grieco et al, 2019 ⁵³	Descriptive-analytic Prospective	58	1 - 15 yrs BT: posterior fossa	Speech: diagnosis of CMS by observation from treating physician Language: standardised assessment of receptive and expressive vocabulary	OTP OFuP	Inpatient Outpatient	31% of cases receiving radiotherapy for posterior fossa tumour had CMS and poor expressive vocabulary in the acute period after treatment
Levy et al, 2013 ⁵⁴	Descriptive Retrospective	13	2.9 - 13.9 yrs Leukaemia: mixed	Neurocognitive testing which showed speech/language difficulties	OFuP SP	Outpatient	69% of cases who had received total body irradiation as a treatment for leukaemia had language and/or speech difficulties at least one-year post-treatment

<p>Richter, Schoch, Kaiser et al, 2005⁵⁵</p>	<p>Analytic Prospective</p>	<p>12 (+27 controls)</p>	<p>9 - 19 yrs BT: posterior fossa</p>	<p>Speech: syllable-repetition and sentence-production tasks, observation in spontaneous sample. Language: Noun/verb generation task, two subtests from standardised aphasia test examining receptive language and written language, standardised developmental language assessment</p>	<p>OFuP SP</p>	<p>Outpatient</p>	<p>Compared to control group, BT group did not differ in their verb and noun generation, receptive language, written language or speech production skills. None of the cases in the BT group had language difficulties or dysarthria</p>
<p>Riva & Giorgi, 2000⁵⁶</p>	<p>Descriptive Retrospective</p>	<p>26</p>	<p>6.0 - 13.4 yrs BT: posterior fossa</p>	<p>Language: Standardised language assessments, mean length of utterance, observations in spontaneous sample. Speech: observations in spontaneous sample</p>	<p>OTP OFuP</p>	<p>Inpatient Outpatient</p>	<p>All cases displayed receptive and expressive language difficulties. 54.5% of cases with medulloblastoma experienced mutism post-surgery with subsequent speech or language difficulties</p>
<p>Robertson et al, 2006⁵⁷</p>	<p>Analytic Prospective</p>	<p>450</p>	<p>Range not reported. Median age at dx with CMS 7.3 yrs; those without CMS 8.0 yrs BT: posterior fossa</p>	<p>CM survey, general assessment of neurological and developmental outcomes (including speech and language) at 1 year post surgery</p>	<p>OTP OFuP</p>	<p>Inpatient Outpatient</p>	<p>24% of cases developed CMS post-surgery, with 92% diagnosed as either moderate or severe. Speech and language dysfunction noted at 1-year post-surgery in 66% of children who had been diagnosed with CMS</p>
<p>Taylor et al, 2012⁵⁸</p>	<p>Descriptive Retrospective</p>	<p>47</p>	<p>Range not reported. All ≤16 yrs Leukaemia and BT</p>	<p>Presence/absence of communication difficulties</p>	<p>OTP OFuP</p>	<p>Inpatient Outpatient</p>	<p>For cases with leukaemia: 34.6% had receptive language disorder, 42.3% expressive language disorder, 26.9% speech disorder, 3.8% pragmatics, and 3.8% had a literacy disorder. For cases with BT: 38.1% had a receptive language disorder, 42.9% had an expressive language disorder, 38.1% had a speech disorder, 14.3% pragmatics, 9.5% had a voice disorder</p>

Abbreviations: BT, brain tumour; ALL, Acute Lymphoblastic Leukaemia; PFS, Posterior Fossa Syndrome; CM, Cerebellar Mutism; CMS, Cerebellar Mutism Syndrome; Dx/IPT, at diagnosis/pre-treatment; OTP, oncology treatment phase; OFuP, oncology follow-up phase; SP, survivorship phase; PFS, Posterior Fossa Syndrome

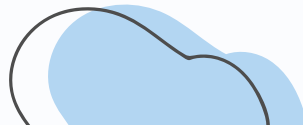


Table 3

Characteristics of included studies: Swallowing (adapted from Hodges et al³)

Citation	Study design	No of participants	Age (range) & cancer type	Outcome measure	Timing	Setting	Key findings
Brannon Morris et al, 2009¹¹	Descriptive Prospective	42	8 months - 22.7 yrs BT: posterior fossa	Observational rating scale	OTP OFuP SP	Inpatient Outpatient	29% of cases with BT had dysphagia at baseline (within 3 months of treatment), 24% at 3 years post-radiotherapy and 21% at 5 years post-radiotherapy
Fayoux et al, 2011⁵⁹	Descriptive Retrospective	5	0.11 - 4.4 yrs BT: brainstem tumour, vagal ganglioneuroma	Observational, videofluoroscopy	Dx/PT OTP OFuP	Inpatient Outpatient	40% of cases had swallowing difficulties pre-surgery. 100% of cases had swallowing difficulties immediately post-surgery and received pharyngoplasty surgery. By 1-month post-pharyngoplasty surgery, swallowing difficulties resolved in all cases and no dysphagia seen at follow-up time point (mean of 33 months later)
Goncalves et al, 2008⁵²	Descriptive Prospective	190	1 - 20 yrs BT: mixed	Patient-reported swallowing problem, direct screening of presence/absence of swallowing difficulties	OTP	Inpatient	Based on patient reported difficulties, 41% of the sample had swallowing difficulties. Based on direct assessment by SLP, 17% of the sample had swallowing difficulties
Hanna et al, 2016⁶⁰	Descriptive Prospective	46	2 - 12 yrs Leukaemia: ALL	Clinical examination by dentist. Dysphagia considered among other dental/oral problems	Dx/PT OTP	Inpatient	Dysphagia included as part of broad oral examination by dentist pre- and post- chemotherapy. No cases had dysphagia pre-chemotherapy. 22% of cases had dysphagia post-chemotherapy
Lee et al, 2016⁶¹	Descriptive Retrospective and prospective	183 cases reviewed; 39 with swallowing difficulties examined	0 - 18.9 yrs BT: posterior fossa	Review of records; clinical examination and videofluoroscopy	OTP OFuP	Inpatient Outpatient	21% of cases reviewed had post-surgery swallowing difficulties. These cases were further explored at two time points: early post-surgery and 1-year post-surgery. Early post-surgery, most needed tube feeding. At one-year post-surgery, some still required modified diets or tube feeding
Mei & Morgan, 2011²¹	Descriptive Retrospective	27	2.0 - 13.8 yrs BT: posterior fossa	Clinical observation of presence/absence of swallowing difficulties. Two cases had videofluoroscopy post-surgery	Dx/PT OTP OFuP	Inpatient Outpatient	11% of cases had dysphagia pre-surgery and 33% had dysphagia post-surgery. Diet modifications and/or tube feeding were required

Morgan et al, 2008 ⁶²	Descriptive Retrospective	11	3.6 - 13.5 yrs BT: posterior fossa	Clinical evaluation with a criterion-referenced tool to examine presence, severity and characteristics of dysphagia. At 2-months post-surgery, parent report via phone call	Dx/PT OTP OFuP	Inpatient Outpatient	Dysphagia not seen in any cases pre-surgery. Post-surgery, 73% had dysphagia which was mild in most cases, although two cases required supplemental tube feeding. At 2-months post-surgery, 75% of children managing normal diet
Nagy et al, 2019 ⁶³	Descriptive Retrospective	19	0.11 - 17 yrs BT: mixed	Clinical observation plus videofluoroscopy in some cases	OTP	Inpatient	All cases examined experienced vocal fold paralysis and subsequent dysphagia post cancer treatment. 42% of cases had frank aspiration. All cases received some form of swallowing management. Management lead to improved swallowing in 84% of cases
Newman et al, 2006 ⁶⁴	Descriptive Retrospective	127 cases reviewed; 24 included for further examination	0.8 - 17.9 yrs BT: posterior fossa	Videofluoroscopy	OTP	Inpatient	19% of cases (24/127) referred for swallowing evaluation post-surgery. Range of swallowing difficulties observed in these cases varied from oral transit difficulties to frank aspiration
Ribeiro et al, 2017 ⁶⁵	Descriptive Prospective	42	2 - 18 yrs Leukaemia: ALL	A criterion-referenced oral assessment tool included section on swallowing	OTP	Inpatient	Swallowing difficulties observed in 7% of cases 1 week after diagnosis and 9.5% of cases 10 weeks after leukaemia diagnosis
Taylor et al, 2012 ⁵⁸	Descriptive Retrospective	47	Range not reported. All ≤16 yrs Leukaemia and BT	Presence/absence of swallowing difficulty	OTP OFuP	Inpatient Outpatient	23% of cases with leukaemia had swallowing difficulties; 71% of cases with BT had swallowing difficulties

Abbreviations: BT, brain tumour; ALL, Acute Lymphoblastic Leukaemia; Dx/PT, at diagnosis/pre-treatment; OTP, oncology treatment phase; OFuP, oncology follow-up phase;

SP, survivorship phase

Individual quality assessment and GRADE certainty of evidence

Each individual study was appraised using the appropriate JBI critical appraisal tool, resulting in a numerical score to reflect elements of risk of bias as shown in the individual quality assessment and GRADE certainty of evidence tables (Tables 4-7). Individual study appraisal indicated methodological shortcomings in the majority of studies. The body of evidence (GRADE) certainty rating for outcomes (communication [sub-divided into speech, language, speech+language] and swallowing) was 'very low' certainty as agreed upon

by the Project Co-ordinator, Chair and Research and Evidence Consultant. These 'very low' certainty ratings were given as serious or very serious concerns were identified for the majority of the five GRADE parameters (risk of bias, inconsistency, publication bias, imprecision, indirectness) for each outcome as seen in Tables 4-7.

Narrative summaries of findings

The key findings per outcome (communication and swallowing) have been synthesised and presented in the "GRADE summary of findings table" (Table 8).



Table 4

Individual quality assessment and GRADE certainty of evidence: Speech

Citation	JBI appraisal score	Certainty of evidence(GRADE)	Risk of bias	Serious concerns
Beckwitt et al, 2012	9/10		Inconsistency	No concerns
Brannon Morris et al, 2009	10/10		Publication bias	Not detected
Catsman-Berrevoets et al, 1999	7/10		Imprecision	Very serious concerns
Cornwell et al, 2005	7/10		Indirectness	No concerns
Cornwell et al, 2003	5/11		Overall certainty	Very low
Cornwell et al, 2004	5/11			
De Smet et al, 2012	8/10			
Huber et al, 2007	4/11			
Korah et al, 2010	10/10			
Kotil et al, 2008	9/10			
Kupeli et al, 2011	6/11			
Liu et al, 2018	10/10			
Mei & Morgan, 2011	9/10			
Morgan et al, 2011	6/11			
Ozimek et al, 2004	2/10			
Richter, Schoch, Ozimek et al, 2005	4/11			
Van Mourik et al, 1998	6/11			
Wells et al, 2010	6/10			

Table 5

Individual quality assessment and GRADE certainty of evidence: Language

Citation	JBIR appraisal score	Certainty of evidence(GRADE)	Risk of bias	Serious concerns
Ait Khelifa-Gallois et al, 2015	5/11		Inconsistency	No concerns
Docking et al, 2016	6/11		Publication bias	Not detected
Docking et al, 2003a	5/11		Imprecision	Very serious concerns
Docking et al, 2003b	5/11		Indirectness	No concerns
Docking et al, 2004	4/11		Overall certainty	Very low
Docking et al, 2005	4/11			
Dowling et al, 2014	5/11			
Kirschen et al, 2008	4/11			
Lafay-Cousin et al, 2009	10/10			
Levisohn et al, 2000	7/10			
Lewis & Bohan, 2018	9/10			
Lewis & Murdoch, 2011	5/11			
Lewis & Murdoch, 2013	5/11			
Lewis et al, 2011	5/11			
Lonnerblad et al, 2017	10/10			
Murdoch et al, 2004	5/11			
Palmer et al, 2014	8/13			

Table 6

Individual quality assessment and GRADE certainty of evidence: Speech+language

Citation	JBI appraisal score	Certainty of evidence(GRADE)	Risk of bias	Serious concerns
Aarson et al, 2004	9/10		Inconsistency	No concerns
Catsman-Berrevoets & Aarson, 2010	10/10		Publication bias	Not detected
Chieffo et al, 2014	10/10		Imprecision	Serious concerns
De Smet et al, 2009	7/10		Indirectness	No concerns
Di Rocco et al, 2011	10/10		Overall certainty	Very low
Di Rocco et al, 2010	10/10			
Frank et al, 2007	6/11			
Frank et al, 2008	7/11			
Goncalves et al, 2008	9/10			
Grieco et al, 2019	5/11			
Levy et al, 2013	9/10			
Richter, Schoch, Kaiser et al, 2005	3/11			
Riva & Giorgi, 2000	5/10			
Robertson et al, 2006	3/10			
Taylor et al, 2012	4/11			

Table 7

Individual quality assessment and GRADE certainty of evidence: Swallowing

Citation	JBI appraisal score	Certainty of evidence(GRADE)	Risk of bias	Serious concerns
Brannon Morris et al, 2009	10/10		Inconsistency	No concerns
Fayoux et al, 2011	8/10		Publication bias	Not detected
Goncalves et al, 2008	9/10		Imprecision	Very serious concerns
Hanna et al, 2016	7/10		Indirectness	No concerns
Lee et al, 2016	10/10		Overall certainty	Very low
Mei & Morgan, 2011	9/10			
Morgan et al, 2008	8/10			
Nagy et al, 2019	7/10			
Newman et al, 2006	8/10			
Ribeiro et al, 2017	9/10			
Taylor et al, 2012	4/11			

Table 8

GRADE summary of findings per outcome (narrative)

Outcome	Summary of key findings (narrative)
<p>Communication</p>	<p>Communication difficulties were frequently reported in children diagnosed with CBTL. Difficulties were seen across both speech and language. Post-operative Cerebellar Mutism Syndrome (pCMS) and/or dysarthria has been identified in children with brain tumours located in the posterior fossa.^{10-26,44,45,47-50,52,53,56,57,66} Some studies have reported mutism resolving to dysarthria and/or language difficulties in these children, in particular.^{15,17,21,23,25,45,47,56,57} Specific speech difficulties described in children diagnosed with brain tumour include: prosody differences,^{13,14,44-46} poor articulation,^{13-15,22,44,46,52} reduced intelligibility^{14,22} and slow speech rate.^{15,22,44,45} Voice problems (e.g. hoarseness, decreased pitch variation/monopitch, roughness, breathiness, instability, hypernasality and tremor)^{13-15,22,25,44,52,58,66} and fluency problems^{16,46,52} have also been identified in children diagnosed with brain tumours. To date, only two studies have reported speech difficulties in children with leukaemia,^{54,58} however, these studies have done so broadly and have not detailed specific speech characteristics. Reported language difficulties in children with CBTL include difficulties with general oral language skills,^{29,31,36,38-40,42,44-49,51-54,56-58} word-finding difficulties,^{36,45,47} discourse level (narrative) difficulties²⁸ and high-level language difficulties.^{30,31,37-40,42} Literacy (reading, writing and spelling) has also been identified as an area of difficulty.^{27,30,31,35,41,44,52} The evidence also highlighted that speech and language difficulties can co-occur in children with CBTL.^{44,46,48,49,51-54,58} The incidence of communication difficulties varied across the literature and therefore a reliable indicator of prevalence could not be reported.</p>
<p>Swallowing</p>	<p>Swallowing difficulties in CBTL were identified in all studies. In studies that described the nature of the dysphagia, difficulties were identified across multiple phases of the swallow (pre-oral anticipatory, oral-preparatory, oral and pharyngeal).^{21,58,62} Aspiration^{63,64} and supplemental feeding during the oncology treatment phase has been reported.^{11,21,58,61,62} Limited evidence on longer-term swallowing prognosis was available but the existing evidence indicated that while most children experience improved swallowing over time, on-going issues can exist for some children.^{11,21,59,61,62} The incidence of swallowing difficulties varied across the literature and therefore a reliable indicator of prevalence could not be reported.</p>

Adapted from narrative synthesis of key findings presented in Hodges et al³

Evidence to Decision Process

The GRADE Evidence to Decision (EtD) framework provides a structured approach for guideline development. The GRADE EtD framework ensures that judgements made during the guideline development process are reported transparently.⁶⁷ In keeping with the GRADE approach to the development of guidelines (<https://www.gradeworkinggroup.org/>), GRADE EtD frameworks were completed by a panel of experts (the Guideline Steering Committee). The results from the EtD were used to inform this guideline (see Figure 9).

GRADE EtD framework methods

The methods have been presented according to the sequential order of the EtD framework: question formulation, making an assessment of the evidence, and drawing conclusions.⁶⁷ The EtD panel of experts (Steering Committee) input was gathered using a combination of online modes reported to be an effective method of engaging experts in the EtD process.⁶⁸

Question formulation and preparation of information

Neutral recommendations were developed based on the clinical questions developed for the systematic review. These clinical questions were provided to the panel of experts (Steering Committee) to consider. For communication, the neutral recommendation was: “Communication assessment and intervention should/should not be offered to children diagnosed with CBTL”. For swallowing, the neutral recommendation was: “Swallowing assessment and management should/should not be offered to children diagnosed with CBTL”.

The EtD was presented to the Steering Committee via an online package developed by the Lead Development team using the software programme, Typeform (<https://www.typeform.com/>). This online package guided the Steering Committee through the evidence assessment process that included the following elements.

Video PowerPoint presentations

Systematic review methods and findings were presented in two PowerPoint presentations (communication and

Figure 9

One source of evidence to inform guidelines: GRADE Evidence to Decision Framework



GRADE = Grading of Recommendations, Assessment, Development and Evaluation

EtD = Evidence to Decision



swallowing) with an audio-recorded voiceover that provided details of the methods and summarised key findings from each of the systematic reviews.

Neutral recommendation

At the end of each PowerPoint presentation, the Steering Committee members were each asked to provide detailed opinions and judgements about the EtD criteria in an online questionnaire.

Online questionnaire

The online questionnaire included the EtD criteria (problem, desirable effects, undesirable effects, values, balance of effects, resources required, cost effectiveness, equity, acceptability, feasibility) and consisted of both multiple choice and open question/answer formats to capture individual responses.

Making an assessment of the evidence

An email was sent to the members of the Steering Committee providing instructions and a hyperlink to access the online Typeform EtD package and questionnaire. The Steering Committee were given six weeks to complete the questionnaire and were invited to contact the Chair or Project Co-ordinator with questions or further information to support their participation. One reminder email was sent after six weeks.

Drawing conclusions

The Typeform responses were downloaded by the Project Co-ordinator and collated into the EtD framework format. All judgements (multiple choice answers) and full comments from the Steering Committee were included for each judgement area of the EtD framework. Judgements were tallied by majority, however raw numbers (judgement of each Steering Committee member) were also retained. The Chair, Project Co-ordinator, and Research and Evidence Consultant completed EtD summary of judgements to final recommendation and determined the strength of recommendations. The Steering Committee were then consulted and asked to provide further input regarding the final recommendation.

GRADE EtD framework results

All nine Typeform EtD online questionnaires were returned (100% return rate) and all were complete. The final two recommendations for both communication and swallowing were unanimously agreed upon. The completed EtD frameworks and summary of judgements to final recommendations for communication can be seen in Tables 9 and 10.

Table 9

GRADE evidence to decision framework and summary of judgements: Communication

Assessment/intervention for communication compared to no assessment/intervention for communication for children diagnosed with CBTL	
Population:	Children aged 0-16 years old diagnosed with CBTL
Prognostic Factors:	Any type of childhood brain tumour or leukaemia
Outcome measures:	Speech and/or language measures
Timing:	Any (At diagnosis/pre-treatment, oncology treatment phase, oncology follow-up phase, survivorship phase)
Setting:	Any (inpatient or outpatient)
Perspective:	The perspective taken here is that of the Guideline Steering Committee. The Steering Committee (panel) was comprised of nine members. This included eight health professionals/clinical researchers with expertise in the field and one consumer (parent of child diagnosed with CBTL).
Background:	Children diagnosed with CBTL may experience a range of communication difficulties across the domains of both speech and language. The findings of the systematic review relative to communication outcomes in this population were provided to the Steering committee before they were asked to make their judgements.

Problem	
Is the problem a priority?	
Judgement ^a	Steering Committee (Panel) Discussion
No	“Interferes with skill development at social, educational level”
Probably no	
Probably yes (3/9)	“Children with CBTL commonly experience communication disorders at some stage during development either in specific areas of language or speech, or globally across all areas. This depends on tumour location, treatment types/combinations, age of the child, time since treatment, tumour type, and associated presenting features such as hydrocephalus”
Yes (6/9)	
Varies	“Although communication may initially be a lower priority (in preference of treating the cancer, mental health, survival), longer term, communication is a real priority as it can determine education, social interactions and more (impacting on quality of life)”
Don't know	“Other impairments often take priority such as balance and tremor, however if not looked for are often overlooked”.
	“We have to minimize the risk of underestimating possible deleterious effects in the long-term (cf. illusory recovery, growing-into-deficits). Doing so implies sustained monitoring via assessments and interventions. Hence my view that communication for children diagnosed with CBTL is indeed a priority”
	“Communication difficulties are evident in children diagnosed with CBTL. The impact of these communication difficulties is likely to be significant - impacting social and academic outcomes. Moreover, the effects may be long-lasting into adulthood with cascading impacts on participation”
	“Communication is a foundational skill which if problematic could have long lasting impacts on the child's quality of life and other functional outcomes such as their ability to complete school, enter university or obtain employment. Communication is also critical for social connectedness, which is essential for young people to maintain good mental health”
	“A moderate priority in the overall scheme”
	“Without communication children cannot express themselves when needed”

Desirable Effects

How substantial are the desirable anticipated effects?

Judgement

Steering Committee (Panel) Discussion

Trivial

"Should be part of multidisciplinary care. Measure to assess, protect and enhance patient's skills and potential are highly valued priorities"

Small

Moderate

Large (8/9)

"The desirable effects are certainly substantial if children with CBTL are offered assessment and treatment for communication. This would allow all children equitable access to improved outcomes for communication development and quality of life. If children are not offered assessment or treatment, the impact to development, communication, socialisation, academic success, and future independence is severely compromised"

Varies (1/9)

Don't know

"Early diagnosis of communication problems (or not) a key way to assist children longer term"

"Social interactions and learning in the classrooms are largely dependent on language so benefits likely to be large"

"The desirable anticipated effects are likely to depend on the great variability of clinical pictures determined by the number and type of intervening factors (e.g., tumor site and size, epilepsy, etc.)"

"The desirable effects of providing assessment and, where needed, intervention, are large. They could have immediate positive impacts for the child and family. Early intervention would likely result in better long-term outcomes. Families feel heard and their concerns/needs are met in a timely manner"

"If you could achieve significant communication improvements, this would have substantial and desirable effects for the child".

"With the ability to communicate children will be able to advocate for their own health and wellbeing, let alone enjoy a more fulfilled life"

Undesirable Effects

How substantial are the undesirable anticipated effects?

Judgement

Steering Committee (Panel) Discussion

Large (1/9)

Moderate

Small (4/9)

Trivial (2/9)

Varies 1/9)

Don't know

“Potential stigmatisation, depends on co-existent morbidities/behavioural issues, parents' priorities”

“It is unlikely that undesirable effects will occur as a result of children with CBTL being routinely offered assessment and early intervention/treatment for communication. It will only serve to reduce the burden on services later in development if disorders go undetected and untreated, and require more extensive intervention later in development; or if undiagnosed at all, the impact to quality of life to children & families is likely considerable, as is the potential burden on society”

“Excess testing is a real issue that can lead to anxiety, over-diagnosis, and general feelings of being overwhelmed (both children and their significant others)”

“Perhaps related to anger or frustration in the child facing his/her communication deficits”

“May be some undesirable effects related to stress on family by providing this assessment or intervention while the priority is still the medical care/survival. May be just one more thing to worry about. However, it is important that they are provided with information about the possible communication impacts so they can make an informed decision”

“I wouldn't expect many undesirable effects from communication assessment and intervention. There may be some distress for parents who learn that their child has a communication difficulty, but this would be more than outweighed by the potential benefits of treatment”

“Without an ability to communicate, there could be grave impacts on a child's health status”

Certainty of evidence

What is the overall certainty of the evidence of effects?

Judgement

Steering Committee (Panel) Discussion

Very low

Low

Moderate

High

No included studies

See Tables 4-6 for GRADE certainty of evidence for communication outcomes (subdivided into speech, language, speech+language)

Values

Is there important uncertainty about or variability in how much people value the main outcomes?

Judgement

Steering Committee (Panel) Discussion

Important uncertainty or variability

Possibly important uncertainty or variability (5/9)

Probably no important uncertainty or variability

No important uncertainty or variability (2/9)

Don't know (2/9)

"Communication- most important. Enables interaction. Provides external measure of self-worth. Enables adaptation and behaviour change"

"Communication (speech and language) are highly valued by children with CBTL and their families. Children with disorders in speech and/language often experience significant impact to quality of life, making friends, school experiences, and academic success. No uncertainty or variability in how much people value speech and language"

"Value of communication (esp. higher level skills) varies greatly - with some families and children valuing it highly"

"English as a second language, age and stage of development of the child will impact the importance placed on language, parental education may also play a role"

"I guess this will probably depend on people's own experiences? Have they been well informed by the different caregivers? Had they already been confronted with a similar situation (e.g., in case of tumor recurrence)?"

“Some members of the MDT may not value it as highly during the acute period where survival is the main outcome. This may also be true for the family”

“Some people might value communication intervention differently, although I think few would disagree that communication skills are foundational for children's wellbeing”

Balance of effects

Does the balance between desirable and undesirable effects favor the intervention or the comparison?

Judgement

Steering Committee (Panel) Discussion

Favors the comparison

“Dependent on individual patient and priorities within families. Overall intervention provides opportunities to vulnerable population”

Probably favors the comparison

“There is no disadvantage to offering communication assessment/intervention when compared to the significant substantial benefits. Routine inclusion in follow-up would allow children to be provided with early intervention and minimise the effects of communication disorders on quality of life”

Does not favor either the intervention or the comparison

Probably favors the intervention

“Favours assessing, and the negatives can be easily mitigated by providing real choice (so if children or their family do not want assessment, it is not mandatory)”

Favors the intervention (8/9)

Varies

“Again if we don't look for the impairments and think about the functional implications left unaddressed can lead to misunderstandings by friends, teachers and family”

Don't know (1/9)

“The benefits in the short and long term of providing appropriate, timely communication assessment and intervention outweigh the possible undesirable effects”

“I expect potential harms would be massively outweighed by potential benefits”

Resources required

How large are the resource requirements (costs)?

Judgement

Steering Committee (Panel) Discussion

Large costs

"Requires individualized approach. ROI hard to ascertain/measure"

Moderate costs (2/9)

Negligible costs
(2/9)

"Cost of employing speech pathologists high short term, but longer term likely to be cost saving (to health, NDIS, family)".

Costs and savings (3/9)

Moderate savings
(1/9)

"There is a negligible cost to incorporating communication assessment/treatment for children with CBTL, however, this is negligible in comparison to the potential burden of more extensive intervention later in development for a disorder that is more established should it be left undiagnosed. The potential public health burden is also more substantial if this rapidly growing population of survivors is left untreated, as reports highlight that children, adolescents and young adults with communication disorders can experience significant impact to quality of life outcomes, as well as low self-esteem, lack of independence, and can also form a percentage of juvenile delinquency rates"

Large savings

Varies

Don't know

"Provides opportunity for early intervention to minimise later larger problems or misunderstandings"

"Most probably important savings in the long-term in case of early intervention and follow-up, by reducing the need for a prolonged management of residual deficits (and hopefully, by preventing sliding into growing-into-deficits)"

"Short-term costs - staff and upskilling staff to provide the Ax and Rx. Savings - in the longer-term for the educational and health systems due to decreased impacts of communication difficulties"

"I expect that high quality assessment and intervention would involve time from experienced staff. I don't think there would be a large cost for equipment"

"Surely with the implementation of technology, this would not incur a huge cost"

"More efficient healthcare provided if a child can advocate for themselves"



Certainty of evidence of required resources

What is the certainty of the evidence of resource requirements (costs)?

Judgement

Steering Committee (Panel) Discussion

Very low

Low

Moderate

High

No included studies

Cost effectiveness

Does the cost-effectiveness of the intervention favor the intervention or the comparison?

Judgement

Steering Committee (Panel) Discussion

Favors the comparison

“Enhances subsequent opportunities for patient in terms of skill/knowledge acquisition. Potentially neutralises or diminishes psychological stress in parents, family members”

Probably favors the comparison

Does not favor either the intervention or the comparison

“As stated, the cost of providing assessment/intervention is negligible compared to the cost of treating more long-term, established disorders later in development, when a broader impact has taken place. Intervention often requires more intensive approaches across larger timeframes”

Probably favors the intervention (3/9)

“Need cost benefit studies in this field”

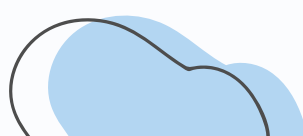
Favors the intervention (5/9)

Varies

“There would be an initial cost but in the longer-term providing this early communication intervention would be cost effective”

Don't know (1/9)

“I'm not on top of the literature about the cost effectiveness of assessment/intervention in this space, but if good outcomes were achieved this could have substantial cost benefits to society (e.g. improved educational/employment outcomes) and families”



Equity

What would be the impact on health equity?

Judgement

Steering Committee (Panel) Discussion

Reduced

"[Equity increased] not only for disadvantaged families/pts, also those from different cultures/non-English speaking background"

Probably reduced
(1/9)

Probably no impact

"Offering assessment/intervention routinely to all children with CBTL ensures an equitable approach across all demographics, cultures, rural and remote regions, and economic backgrounds - thereby improving access to necessary healthcare for all"

Probably increased
(2/9)

Increased (6/9)

"CALD groups, children who use AAC, families with low literacy, families/children in rural areas - likely not to have the same level of immediate access as those in big city hospitals, high literacy and English speaking"

Varies

Don't know

"If a national guideline was implemented with a minimum standard for communication assessment/intervention, this would lead to greater equity of services across different population groups"

"I would expect disadvantaged groups would be more likely to benefit if offered to all families, as they are less likely to have the resources to seek private services for their child"

"It would ensure a more just approach to all and provide inclusivity regardless of status etc..."

"At present there are no guidelines limiting equity of access"

Equity

What would be the impact on health equity?

Judgement

Steering Committee (Panel) Discussion

No

“Highly valued”

Probably no

Probably yes (1/9)

Yes (6/9)

Varies

Don't know (2/9)

“Offering communication assessment/treatment is a routine practice in the field of communication/speech pathology. This will allow all children to access this service in a timely manner at the best time in their care following cancer treatment and follow-up”

“Brain tumors are complex and can impact all aspects of function and participation so should be very acceptable”

“Most MDT members would find it acceptable. Some may not view it as a priority during the acute period and thus not accept it. Education to MDT members who work with these populations on the importance of communication could help to mitigate this”

“I don't think many people would find it unacceptable”

Feasibility

Is the intervention feasible to implement?

Judgement

Steering Committee (Panel) Discussion

No

“Should be part of initial assessment just as we currently assess psychosocial needs”

Probably no

Probably yes (2/9)

Yes (6/9)

Varies (1/9)

Don't know

“Implementation of communication assessment is highly feasible to incorporate into existing cancer follow-up services currently offered to children with CBTL. Children will be referred to appropriate existing services for treatment. No further widespread services are required to be introduced”



"It is feasible but \$\$\$ to employ SLPs needed across the country (not just city)"

"Depends on staffing and funding"

"Depends, among others, on geographical distance between caregivers and patients, and on Tele-facilities".

"The number of children diagnosed with CBTL nationally each year is not large so it is feasible. All children with CBTL have contact with a major children's hospital as part of their cancer treatment so it is feasible to embed the communication management into this care"

"Apart from staff time, I don't anticipate any major barriers to implementation"

"Communication is fundamental"

"These are basic practices applied in other acute and chronic care settings"

^aThe most frequently identified judgement is bolded, tallies of judgements are included in brackets

Summary of judgements: Communication

	Judgement						
Problem	No	Probably no	Probably yes	Yes		Varies	Don't know
Desirable Effects	Trivial	Small	Moderate	Large		Varies	Don't know
Undesirable Effects	Large	Moderate	Small	Trivial		Varies	Don't know
Certainty of evidence	Very low	Low	Moderate	High			No included studies
Values	Important uncertainty or variability	Possibly important uncertainty or variability	Probably no important uncertainty or variability	No important uncertainty or variability			
Balance of effects	Favors the comparison	Probably favors the comparison	Does not favor either the intervention or the comparison	Probably favors the intervention	Favors the intervention	Varies	Don't know
Resources required	Large costs	Moderate costs	Negligible costs	Costs and savings	Savings	Varies	Don't know
Certainty of evidence of required resources	Very low	Low	Moderate	High			No included studies
Cost effectiveness	Favors the comparison	Probably favors the comparison	Does not favor either the intervention or the comparison	Probably favors the intervention	Favors the intervention	Varies	No included studies
Equity	Reduced	Probably reduced	Probably no impact	Probably increased	Increased	Varies	Don't know
Acceptability	No	Probably no	Probably yes	Yes		Varies	Don't know
Feasibility	No	Probably no	Probably yes	Yes		Varies	Don't know

Recommendation

Communication assessment/intervention should be offered to children diagnosed with childhood brain tumour or leukaemia.

Types of recommendation

Strong recommendation against the intervention	Conditional recommendation against the intervention	Conditional recommendation for either the intervention or the comparison	Conditional recommendation for the intervention	Strong recommendation for the intervention
○	○	○	○	●



Table 10

GRADE Evidence to Decision framework and summary of judgements: Swallowing

Assessment/intervention for communication compared to no assessment/intervention for communication for children diagnosed with CBTL	
Population:	Children aged 0-16 years old diagnosed with CBTL
Prognostic Factors:	Any type of childhood brain tumour or leukaemia
Outcome measures:	Swallowing measures
Timing:	Any (At diagnosis/pre-treatment, oncology treatment phase, oncology follow-up phase, survivorship phase)
Setting:	Any (inpatient or outpatient)
Perspective:	The perspective taken here is that of the Guideline Steering Committee. The Steering Committee (panel) was comprised of nine members. This included eight health professionals/clinical researchers with expertise in the field and one consumer (parent of child diagnosed with CBTL).
Background:	Children diagnosed with CBTL may experience swallowing difficulties. The findings of the systematic review relative to swallowing outcomes in this population were provided to the Steering committee before they were asked to make their judgements.

Problem	
Is the problem a priority?	
Judgement ^a	Steering Committee (Panel) Discussion
	“Nutritional issues, acute health care concerns, independence, social interaction, schooling, fitting in with peers, appearance”

No	“Significant priority, as it can be both an immediate and longer term issue that can not only effect quality of life (mealtimes, feeding, socialisation), but also involves the potential for risk of aspiration/pneumonia/mortality in these children”
Probably no	
Probably yes (3/9)	
Yes (6/9)	“Potentially life threatening, plus impact on quality of life”
Varies	
Don't know	“Depends on symptoms at the bedside, clinicians need to know to think about swallowing as much as they think about temperature post-op”
	“It will help detect inconspicuous problems, and, thus, reduce the frequency of untreated difficulties”
	“Definitely yes in the short-term due to potentially life-threatening problems if swallowing is not prioritised”
	“For children with a swallowing difficulty it is clearly a priority, but it possibly is less common and less long lasting than communication difficulties”
	“There is a need for all children”
	“It is a priority but not all children have swallowing challenges -it depends more on the site of the tumour”

Desirable Effects

How substantial are the desirable anticipated effects?

Judgement ^a	Steering Committee (Panel) Discussion
Trivial	“Assessments should be part of multidisciplinary care”
Small	
Moderate (2/9)	“These cannot be understated. Imperative that swallowing is assessed and treated without delay, due to the significant consequences if left untreated”
Large (7/9)	
Varies	“Given the potential impact of dysphagia, the desirable effects of ensuring safe swallowing are important”
Don't know	“Prevent aspiration, safe swallowing of fluids and solids”

“Potentially life-saving. Crucial for safe swallowing”

“Swallowing intervention would be very important for those children experiencing difficulties”

“Reducing aspiration risk is important to prevent onset of pneumonia or chest infections and other complications that would have negative impacts on health”

“With the ability to communicate children will be able to advocate for their own health and wellbeing, let alone enjoy a more fulfilled life”

Undesirable Effects

How substantial are the undesirable anticipated effects?

Judgement^a

Steering Committee (Panel) Discussion

Large (2/9)

“Highly valued”

Moderate (1/9)

Small (3/9)

“No undesirable effects if swallowing assessment/treatment offered, in comparison to substantial life-threatening and impacting outcomes if not”

Trivial (2/9)

Varies

“Given that swallowing assessment is normally brief, the negative effects relate mainly to anxiety”

Don't know (1/9)

“Aspiration pneumonia can be an expensive complication of brain tumor treatment”

“May be some stress on child and family”

“I don't anticipate any undesirable effects, apart from impact on staff time and burden on families for the intervention”

“Listen to the consumer- parents often know best about their child”

“Aspiration due to swallowing difficulties could cause chest infections or pneumonia and gravely impact health for children who are already very unwell”

Certainty of evidence

What is the overall certainty of the evidence of effects?

Judgement^a

Steering Committee (Panel) Discussion

Very low

See Table 7 for GRADE certainty of evidence

Low

Moderate

High

No included studies

Values

Is there important uncertainty about or variability in how much people value the main outcomes?

Judgement^a

Steering Committee (Panel) Discussion

Important uncertainty or variability

“Eating is a major social interaction which helps to bind relationships. Assessment and potential subsequent intervention - important and valued”

Possibly important uncertainty or variability (3/9)

“Importance of assessing and managing swallowing disorders well established”

Probably no important uncertainty or variability (2/9)

“Often not considered. Speech and OT and PT need to be part of the post op care of children with brain tumors or leukaemia”

“This depends, among others, on how well informed they have been, as well as on their possible previous experiences”

No important uncertainty or variability (4/9)

“I think all would value it highly”

“Some health professionals may disagree about how important swallowing is if most of their patients do not have difficulties”

“Swallowing - or rather - risks of swallowing disorder(s) -are poorly understood

Balance of effects

Does the balance between desirable and undesirable effects favor the intervention or the comparison?

Judgement^a

Steering Committee (Panel) Discussion

Favors the comparison

"As stated, imperative that swallowing assessment/management is offered. The risks are too substantial if it is not"

Probably favors the comparison

"Ensuring that children with CBTL are safe is important with minimal negative effect"

Does not favor either the intervention or the comparison

"Needs more information to support a stronger recommendation but the gut feeling is likely to favour"

Probably favors the intervention (4/9)

"Benefits definitely outweigh undesirable effects"

Favors the intervention (5/9)

"Swallowing assessment/intervention would be valuable for children who have difficulty in this area"

Varies

Don't know

"All assessments have merit for children who are dealing with these cancers"

"Prevention of pneumonia is important"

Resources required

How large are the resource requirements (costs)?

Judgement^a

Steering Committee (Panel) Discussion

Large costs

"Important for independence, socialising, playing, and self-esteem"

Moderate costs (1/9)

Negligible costs (6/9)

"Negligible resources required for a substantial positive outcome; and an intolerable outcome if not offered"

Costs and savings

"Note that although speech pathologists are highly skilled to provide swallowing assessment, others can be trained to assist with intervention plans"

Moderate savings

Large savings

"Needs analysis"

Varies

Don't know (2/9)

"Resources to provide swallowing assessment and management are already there in the acute setting. Longer-term swallowing follow-up may require additional resources in terms of staff, staff education and ax tools"

"I expect health professional time will again be the primary resource needed"

"A clear need has been mentioned"

"A brief swallowing assessment with careful recommendations made by and SLP need not be time consuming"

"More efficient healthcare provided if a child can advocate for themselves"

Certainty of evidence of required resources

What is the certainty of the evidence of resource requirements (costs)?

Judgement^a

Steering Committee (Panel) Discussion

Very low

Low

Moderate

High

No included studies



Cost effectiveness

Does the cost-effectiveness of the intervention favor the intervention or the comparison?

Judgement^a

Steering Committee (Panel) Discussion

Favors the comparison

“Should be part of multidisciplinary assessment and support”

Probably favors the comparison

“Again, if swallowing disorders left untreated the cost of healthcare for a child with respiratory compromise or aspiration pneumonia is significantly higher over a longer period of time”

Does not favor either the intervention or the comparison

“Needs research”

Probably favors the intervention (2/9)

“Definitely cost effective to provide as it outweighs potential costs of swallowing problems and flow-on effects (e.g, aspiration then pneumonia)”

Favors the intervention (6/9)

Varies

“I’m not sure of the evidence in this area”

Don’t know (1/9)

“As it will assist in the long term journey of the child affected”

“Offsetting chest infections and pneumonia would prevent tests and medications for these conditions and reduce length of stay potentially depending at what stage of cancer treatment children are experiencing at the time”

Equity

What would be the impact on health equity?

Judgement^a

Steering Committee (Panel) Discussion

Reduced

“[Equity increased] for NESB patients/families and socially/financially disadvantaged groups”

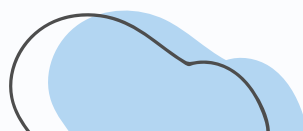
Probably reduced (1/9)

Probably no impact

“Offering swallowing assessment/management to all children will ensure an equitable approach for all children”

Probably increased (1/9)

“need more data”



Increased (5/9)

Varies

Don't know (2/9)

“As per communication, a national guideline mandating minimum swallowing ax/mx would ensure all kids have access and thus improve equity”

“Universal assessment is more likely to benefit disadvantaged families who may be less likely to recognise their child's difficulties or less able to advocate for services for their child”

“All would be able to access this assessment in a just way”

“If there could be targeted guidelines about who to prioritise for swallowing assessment/intervention this would be a vast improvement on the current status quo”

Acceptability

Is the intervention acceptable to key stakeholders?

Judgement^a

Steering Committee (Panel) Discussion

No

“Crucial component of supportive care”

Probably no

Probably yes (1/9)

“As the risks and negative outcomes associated with not providing swallowing assessment/intervention are not acceptable”

Yes (7/9)

Varies

“Likely to be acceptable to most”

Don't know (1/9)

“[yes] obvious”

“Yes - MDT team members would find it acceptable and necessary. Families may need education on its importance before accepting it”

“I expect it would be acceptable”

“Evidence based”

“The assessment and interventions for dysphagia should be acceptable”



Feasibility

Is the intervention feasible to implement?

Judgement^a

Steering Committee (Panel) Discussion

No

“Part of MDT assessment when providing comprehensive care to children with cancer and their families”

Probably no

Probably yes (1/9)

Yes (6/9)

“Again, existing services can implement this recommendation in existing follow-up care models. If not implemented, healthcare services will be over-burdened due to the negative outcomes that may result”

Varies (2/9)

Don't know

“Easy to implement as long as there are SLPs”

“Depends on staffing and funding”

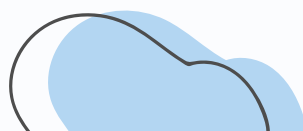
“Depends, among others, on geographical distance between caregivers and patients, and on Tele-facilities”

“As per communication, these children already have contact with major children hospital so feasible for them to provide in both short and longer-term”

“It might depend on the resources available at each children's hospital”

“Again - brief swallowing assessment is not onerous and just relies on SLP time”

^aThe most frequently identified judgement is bolded, tallies of judgements are included in brackets



Summary of judgements: Swallowing

	Judgement						
Problem	No	Probably no	Probably yes	Yes		Varies	Don't know
Desirable Effects	Trivial	Small	Moderate	Large		Varies	Don't know
Undesirable Effects	Large	Moderate	Small	Trivial		Varies	Don't know
Certainty of evidence	Very low	Low	Moderate	High			No included studies
Values	Important uncertainty or variability	Possibly important uncertainty or variability	Probably no important uncertainty or variability	No important uncertainty or variability			
Balance of effects	Favors the comparison	Probably favors the comparison	Does not favor either the intervention or the comparison	Probably favors the intervention	Favors the intervention	Varies	Don't know
Resources required	Large costs	Moderate costs	Negligible costs	Costs and Savings	Savings	Varies	Don't know
Certainty of evidence of required resources	Very low	Low	Moderate	High			No included studies
Cost effectiveness	Favors the comparison	Probably favors the comparison	Does not favor either the intervention or the comparison	Probably favors the intervention	Favors the intervention	Varies	No included studies
Equity	Reduced	Probably reduced	Probably no impact	Probably increased	Increased	Varies	Don't know
Acceptability	No	Probably no	Probably yes	Yes		Varies	Don't know
Feasibility	No	Probably no	Probably yes	Yes		Varies	Don't know

Recommendation

Swallowing assessment and management should be offered to children diagnosed with childhood brain tumour or leukaemia.

Types of recommendation

Strong recommendation against the intervention	Conditional recommendation against the intervention	Conditional recommendation for either the intervention or the comparison	Conditional recommendation for the intervention	Strong recommendation for the intervention
○	○	○	○	●



Health Professional and Consumer Survey

To complement the systematic review evidence and the EtD process, a Health Professional and Consumer Group survey was undertaken (see Figure 10). Through this, the perspectives and experiences of health professionals working in the area of CBTL and consumers were gathered. The findings from the Health Professional and Consumer Group survey have also been prepared in the form of a journal article for submission to a peer-reviewed journal in the field (Chami et al⁶⁹). The methods and results of the Health Professional and Consumer Group survey are detailed below.

Survey methods

Participant recruitment

Multidisciplinary health professionals with experience in CBTL and consumers (adult survivors of CBTL or parents of children diagnosed with CBTL) were recruited to be part of the Health Professional and Consumer Group. The role of the Health Professional and Consumer Group was to complete a survey asking about their experiences and perspectives on the management of communication and swallowing for children diagnosed with CBTL. A variety of recruitment strategies were

used as detailed in Figures 11 and 12. The survey was given ethical approval through the University of Sydney Human Research Ethics Committee review process (Project number: 2018/507).

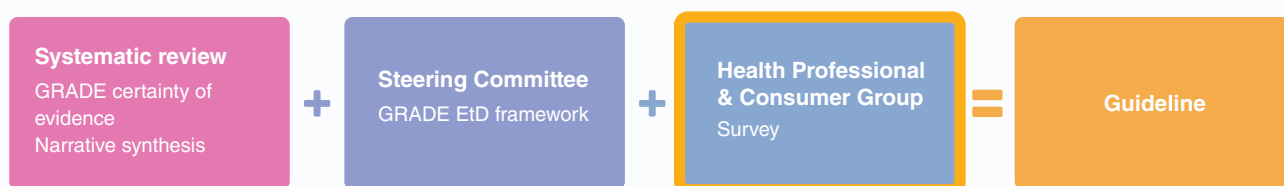
Survey design and content

The survey was drafted by the Chair, Project Co-ordinator and Research Assistants, Ms Sara Chami and Ms Emma Campbell. It was developed using the software program, Qualtrics (<https://www.qualtrics.com/>). Draft versions were sent to the Steering Committee who provided feedback.

The survey included demographic questions specific to health professionals and consumers followed by questions focused on the clinical management of communication and swallowing for children with CBTL. Specifically, clinical questions focused on communication and swallowing assessment and intervention, the multi-disciplinary care team and risk factors. Completing the survey took approximately 30-45 minute and could be done on a computer, tablet or mobile device. Question types included binary choice (e.g., yes/no), multiple-choice and 5-point Likert scales. Likert scales included

Figure 10

One source of evidence to inform guidelines: Health Professional and Consumer survey



GRADE = Grading of Recommendations, Assessment, Development and Evaluation

EtD = Evidence-to-Decision

importance questions (rated between “extremely important” and “not at all important”) and agreement questions (rated between “strongly agree” and “strongly

disagree”). Opportunities for free comments via open-ended questions were given throughout the survey.

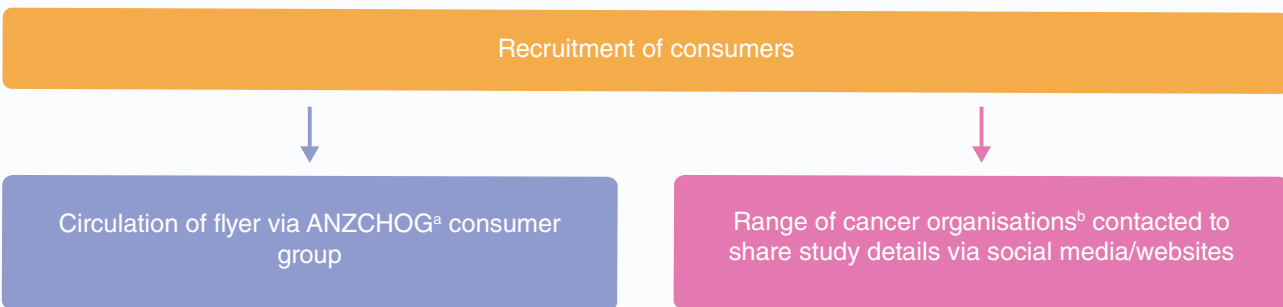
Figure 11

Health professional recruitment



Figure 12

Consumer (parents and survivors) recruitment



^aAustralian and New Zealand Children’s Haematology/Oncology Group

^bCancer organisations contacted: RedKite, Canteen, Cancer Council and the Childhood Cancer Association

Figure 13

Survey data analyses methods

Descriptive statistics

- Used for binary choice, multiple choice Qs and Likert scale Qs
- Tally of responses (n)
- Mean
- Percentages (%)

Qualitative analyses

- Used for open-ended questions
- Identification of themes and sub-themes using Grounded theory

Data analysis

Survey data was analysed in two ways: descriptive statistics and a qualitative analysis using QSR International NVivo12 Qualitative Data Analysis Software (<https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>). Figure 13 details the analyses methods above.

Survey results

Demographics of the Health Professional and Consumer Group

The Health Professional and Consumer Group was comprised of 22 health professionals (20 female) and two consumers, both mothers of children diagnosed with CBTL. The health professionals had an average of over 10 years' experience working with children with CBTL. All health professionals worked in metropolitan children's hospitals (several identified additional workplaces such as private practice or a university). Occupations of the health professionals are shown in Figure 14.

Assessment and intervention for communication and swallowing in CBTL

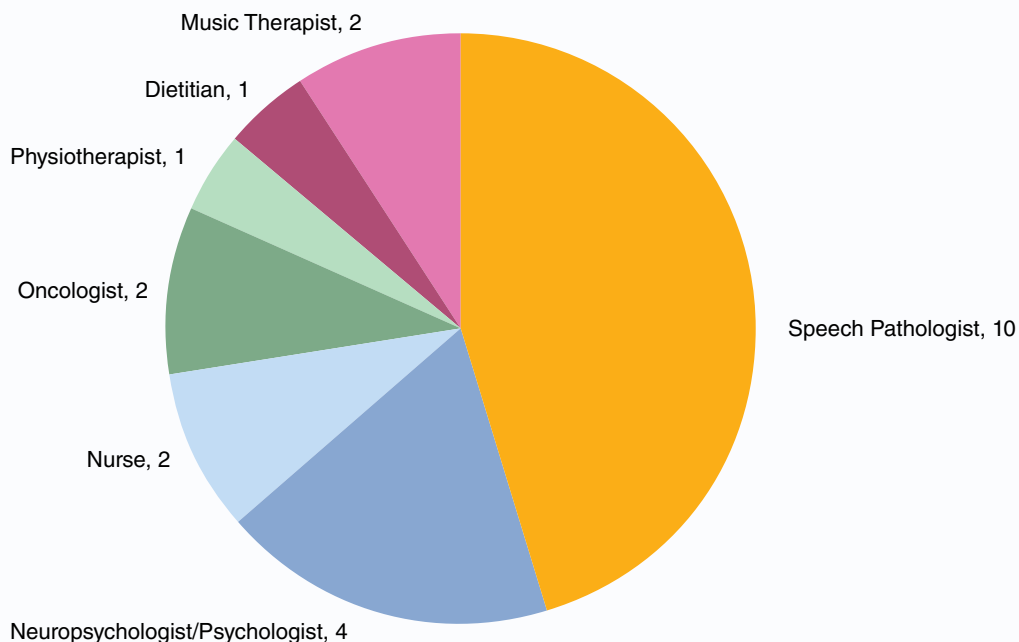
Communication

Comprehensive communication assessment for children with CBTL was identified as extremely/very important by 88% of the Health Professional and Consumer Group. The group also felt strongly that communication assessment contributes to an improvement in speech (88%) and language (92%) outcomes.

Regular assessment of communication across childhood and adolescence was identified as extremely/very important by the majority of the group (62% for speech; 75% for language). Most group members agreed that regular assessment across time would contribute to improved speech (83%) and language (91%) outcomes. In the open-ended questions regarding communication assessment, some group members commented on the need for communication assessment to be individualised, dependent on patient factors and/or other risk factors. The role of monitoring communication skills via methods

Figure 14

Occupations of health professionals who completed the survey





such as screening, phone/telehealth and via schools or other health professionals was also raised as a way to guide timely assessment and intervention for children diagnosed with CBTL.

The provision of intervention for communication difficulties in this population was seen as extremely/very important by 96% of the group and an overwhelming majority (96%) strongly agreed/agreed that it would result in improved speech and language outcomes. The need for communication intervention services to be accessible in the longer-term was raised by multiple members of the group. However, it was also noted that communication intervention may not be a priority for some families during cancer treatment as they could be overwhelmed by medical factors at that time.

Swallowing

The majority of the Health Professional and Consumer Group rated comprehensive swallowing assessment as extremely/very important (83%) for children with CBTL and agreed that it contributes to improved swallowing outcomes (96%). In regard to the timing of swallowing assessment, 63% of the group saw regular swallowing assessments as extremely/very important and 79% strongly agreed/agreed that regular assessment would contribute to an improvement in swallowing outcomes. However, through the open-ended questions, several group members commented on the need for swallowing assessment over time to be guided by individual factors such as patient health and other risk factors.

The need for swallowing intervention was recognised by the group, with 92% rating it as extremely/very important and 96% strongly agreeing/agreeing that it contributes to improved swallowing outcomes. As with assessment, group members commented on the need for intervention decisions to be based on individual factors and results of the swallowing assessment. The need for intervention to reduce long-term feeding problems and improve medical outcomes was also identified through responses to the open-ended questions.

Multidisciplinary team for communication and swallowing in CBTL

Across both communication and swallowing, the need for a collaborative multidisciplinary team (MDT) approach to clinical management for children diagnosed with CBTL was recognised by the majority of the Health Professional and Consumer Group. For communication, a range of health professionals were identified as part of the care team, with the Speech Pathologist being particularly important in direct assessment and management (identified by 92% of the group). Similarly, for swallowing, a range of health professionals were recognised in the care team, with Speech Pathologists again the most frequently identified (identified by 83% of the group). Dietitians were also identified as important for swallowing management by the majority of group (67%). The most frequently reported MDT members and sample quotes for their role in the team are shown in Tables 11 and 12.

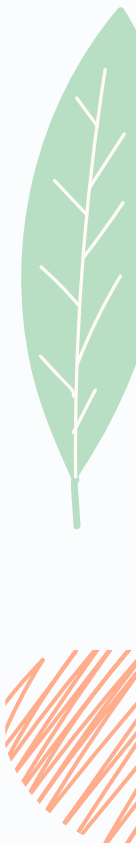
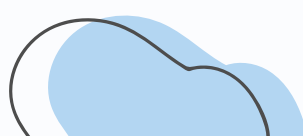


Table 11

Multidisciplinary team (MDT) health professionals involved in communication management (sourced from Chami et al⁶⁹)

MDT Member	Sample Quotes
MDT member tally (n), percentage of total participants (n = 24)	
Speech Pathologist n = 22, 92%	“Experts in managing communication disorders”
Occupational Therapist n = 11, 46%	“Supports fine motor access to communication technology... AAC”
Education (including teachers, educational play therapist) n = 12, 50%	“Need to understand the child’s communication difficulties as they relate to participation in the school environment”
Neuropsychologist n = 10, 42%	“Assess language in relation to other cognitive functioning”
Psychologist/mental health n = 9, 38%	“Support... child in frustrations arising from communication difficulties... understand impact of cognition... mental health on communication”
Medical staff n = 7, 29%	“Monitor effects of treatment on communication”
Paediatrician n = 5, 21%	“Assess... developmental and medical conditions that can predispose the child to communication and learning issues”
Nurse n = 4, 17%	“Day to day care of patients...need to understand the communication strengths and weaknesses of the patient”
Physiotherapist n = 3, 11%	“Breath support, achieve and maintain vocal volume... breathiness... MLU”
Child Life Therapist n = 4, 17%	“Encourage greater communication...”
Family n = 3, 11%	“Provide the daily therapy required”
Oncologist n = 3, 11%	“Insight into any... medication that may impede communication”

Table 12

Multidisciplinary team (MDT) health professionals involved in swallowing management (sourced from Chami et al⁶⁹)

MDT Member MDT member tally (n), percentage of total participants (n = 24)	Sample Quotes
Speech Pathologist n = 20, 83%	"Key professional required for assessment and management of feeding disorders" "...guide hospital staff, the child and parents on the safest oral intake ..."
Dietitian n = 16, 67%	"Management of tube feeding ..." "...ensure adequate nutrition is maintained in the absence of a safe swallow" "...work with the team to determine the oral intake required ..."
Doctors n = 11, 46%	"...lead discussions around the need for NGT/gastrostomy and will order further instrumental assessments (FEES, VFSS; Videofluoroscopy Swallowing Study)." "Ongoing medical management and maintenance. Coordinate MDT" "early detection of changes and timely referral on for management"
Nurse n = 10, 42%	"...manage the consequence of swallowing difficulties and implement modifications or interventions as directed." "Play a key role in feeding back/reporting on observations of the mealtime experience to SP, DT and other members of the MDT"
Occupational Therapist n = 9, 38%	"Heavily involved in sensory feeding interventions, picky eaters, ... mealtime set up, equipment, upper-limb and fine motor function" "Area of specialty"
Physiotherapist n = 6, 25%	"Works with the speech pathologist in oral trials to monitor the chest/respiratory system..." "...informs the best positioning supports and equipment needed so the child can sit up for meals safely / independently."

Oncologist
n = 5, 21%

“... swallow recovery ...provided by the oncologist managing the brain tumor appropriately with surgery/radiation/chemotherapy combination”

“...across the whole care of the patient”

“...advise if any treatment changes etc. that may impact swallowing, etc.”

Psychologist
n = 4, 17%

“...management of behavioral feeding and swallowing issues ...anxiety about food, etc.”

“Capacity building of all staff regarding behavioral management techniques.”

Family
n = 3, 13%

“...carers and providers of meals (in whatever form) it's important for them to be involved at all times.”

“Identification of changes and timely access to support “

Paediatrician
n = 3, 13%

“Provides care coordination, provides education and support to staff, patient, parents and carers”

Risk factors

For communication and swallowing, the Health Professional and Consumer Group believed it to be extremely/very important to consider risk factors when providing management (88% for communication, 92% for swallowing). Qualitative analyses revealed categories of

risk factors that they believed should be considered by health professionals when working with these children (see Box C).

Box C

Risk factors identified by the Health Professional and Consumer Group

Child Factors

- External child factors (e.g. socioeconomic status)
- Pre-morbid difficulties/delays
- Child's age
- Time spent in hospital
- Medical prognosis

Tumour Properties

- Cancer location
- Cancer type
- Existence of cerebellar mutism
- Hydrocephalus
- Tumour size
- Recurrence
- Other complicating factors (infections, cranial nerve damage, peri-surgical complications)

Cancer Treatment

- Treatment type
- Treatment side effects
- Treatment location
- Treatment frequency
- Efficiency of the multidisciplinary team in providing treatment
- Intake type (e.g. prolonged periods of tube feeding)
- Physical positioning (e.g. ability to be in upright position for safe swallowing)

Swallowing Related Factors (for swallowing only)

- Intake type (e.g. prolonged periods of tube feeding)
- Physical positioning (e.g. ability to be in upright position for safe swallowing)








Adapted from Chami et al⁶⁹

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Appendices

Appendix A

Public consultation: Invited organisations

Organisations

American Speech and Hearing Association

Hunter Cancer Research Alliance

ANZCHOG (Australian and New Zealand Childrens Haematology/Oncology Group)

International Association of Logopedics and Phoniatrics

Association of Child Life Therapists Australia

Kids Cancer Alliance

Australian Medical Association

Kids Cancer Project

Australian Music Therapy Association

Leukaemia Foundation

Australian Physiotherapy Association

Occupational Therapy Australia

Australian Primary Healthcare Nurses Association

Pirate Ship Foundation

Australian Psychology Society

Posterior Fossa Society

Brain Tumour Alliance Australia

Red Kite

Cancer Australia

Ronald McDonald House Charities

Cancer Council Australia

Royal Australasian College of Physicians (Paediatrics)

CanTeen

Speech Pathology Australia

Centre for Oncology Education and Research Translation (CONCERT)

Starlight Children's Foundation

Childhood Cancer Association

Sydney Catalyst

Clinical Oncology Society of Australia

Sydney Vital

Consumers Health Forum of Australia

Sydney West Translational Cancer Research Centre

Cure Brain Cancer Foundation

The Royal College of Speech and Language
Therapists

Dietitians Association of Australia

Translational Cancer Research Network

Appendix B

Search strategy used in each database

Medline

Platform: OvidSP

Database coverage: 1946 – present

Date completed: 15th June, 2018 (re-run 21st August, 2019)

- 1 exp "neoplasms, germ cell and embryonal"/ or exp central nervous system neoplasms/ or exp cranial nerve neoplasms/
- 2 (brain adj2 (cancer* or tumo?r*)).mp.
- 3 exp Leukemia/
- 4 (posterior adj2 fossa adj2 syndrome).mp.
- 5 (cerebellar adj2 mutism).mp.
- 6 exp Communication/
- 7 exp Communication Disorders/
- 8 exp Voice Quality/
- 9 exp Voice Disorders/
- 10 ((speech or articulat* or stutter* or voice or vocal) adj3 (disorder* or impair* or problem* or difficult* or outcome* or skill*)).mp.
- 11 ((phonat* or prosod* or intonat*) adj3 (disorder* or impair* or problem* or difficult* or outcome* or skill*)).mp.
- 12 Apraxias/
- 13 (apraxia adj1 speech).mp.

- 14 (posterior adj2 fossa adj2 syndrome).mp.
- 15 (cerebellar adj2 mutism).mp.
- 16 (language adj3 (disorder* or impair* or problem* or difficult* or outcome* or skill*)).mp.
- 17 ((phonolog* or syntax or syntactic or gramma* or semantic* or pragmatic*) adj3 (disorder* or impair* or problem* or difficult* or outcome* or skill*)).mp.
- 18 (social adj2 (skill* or language)).mp.
- 19 narrative*.mp.
- 20 discourse.mp.
- 21 conversation*.mp.
- 22 pre-litera*.mp.
- 23 prelitera*.mp.
- 24 (phon* adj aware*).mp.
- 25 (literacy adj3 (disorder* or impair* or problem* or difficult* or outcome* or skill*)).mp.
- 26 exp Neuropsychology/
- 27 Neurocognitive Disorders/
- 28 exp verbal learning/
- 29 Deglutition Disorders/
- 30 dysphagia.mp.
- 31 (swallow* adj5 (abnormal* or difficult* or disorder* or dysfunc* or function* or impair* or outcome* or skill*)).mp.
- 32 ((academic or school) adj3 (achiev* or success* or fail*)).mp.
- 33 1 or 2 or 3 or 4 or 5
- 34 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32
- 35 33 and 34
- 36 limit 35 to (yr="1988 -Current" and ("all infant (birth to 23 months)" or "all child (0 to 18 years)")) and (adaptive clinical trial or case reports or classical article or clinical study or clinical trial, all or clinical trial, phase i or clinical trial, phase ii or clinical trial, phase iii or clinical trial, phase iv or clinical trial or comparative study or controlled clinical trial or "corrected and republished article" or equivalence trial or evaluation studies or historical article or introductory journal article or journal article or meta analysis or multicenter study or observational study or randomized controlled trial or "review" or systematic reviews or twin study or validation studies))

Embase

Platform: OvidSP

Database coverage: 1947-present

Date completed: 15th June, 2018 (re-run 21st August, 2019)

- 1 exp central nervous system tumor/
- 2 (brain adj2 (cancer* or tumo?r*)).mp.
- 3 exp leukemia/
- 4 (posterior adj2 fossa adj2 syndrome).mp.
- 5 (cerebellar adj2 mutism).mp.
- 6 speech disorder/ or "apraxia of speech"/ or cluttering/ or exp dysarthria/ or echolalia/ or fluency disorder/ or hypernasality/ or muteness/ or nasal speech/ or slurred speech/ or speech sound disorder/ or stuttering/ or exp voice disorder/
- 7 ((speech or articulat* or stutter* or voice or vocal) adj3 (disorder* or impair* or problem* or difficult* or outcome* or skill*)).mp.
- 8 ((phonat* or prosod* or intonat*) adj3 (disorder* or impair* or problem* or difficult* or outcome* or skill*)).mp.
- 9 apraxia/
- 10 (posterior adj2 fossa adj2 syndrome).mp.
- 11 (cerebellar adj2 mutism).mp.
- 12 exp communication disorder/
- 13 (language adj3 (disorder* or impair* or problem* or difficult* or outcome* or skill*)).mp.
- 14 ((phonolog* or syntax or syntactic or gramma* or semantic* or pragmatic*) adj3 (disorder* or impair* or problem* or difficult* or outcome* or skill*)).mp.
- 15 (social adj2 (skill* or language)).mp.
- 16 narrative*.mp.
- 17 discourse.mp.
- 18 conversation*.mp.
- 19 exp literacy/
- 20 pre-litera*.mp.
- 21 prelitera*.mp.
- 22 (phon* adj aware*).mp.

- 23 (literacy adj3 (disorder* or impair* or problem* or difficult* or outcome* or skill*)).mp.
- 24 exp neuropsychology/
- 25 neurocogniti*.mp.
- 26 exp dysphagia/
- 27 ((swallow* or deglutition) adj5 (abnormal* or difficult* or disorder* or dysfunc* or function* or impair* or outcome* or skill*)).mp.
- 28 exp academic achievement/
- 29 1 or 2 or 3 or 4 or 5
- 30 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28
- 31 29 and 30
- 32 limit 31 to (yr="1988 -Current" and (article or article in press or "review") and (infant <to one year> or child <unspecified age> or preschool child <1 to 6 years> or school child <7 to 12 years> or adolescent <13 to 17 years>))

CINAHL

Platform: EbscoHost

Database coverage: 1982-present

Date completed: 15th June, 2018 (re-run 21st August 2019)

S1 (MH "Neoplasms, Germ Cell and Embryonal+") OR (MH "Neoplasms, Glandular and Epithelial+") OR (MH "Neoplasms, Nerve Tissue+") OR (MH "Central Nervous System Neoplasms+")

S2 (brain N2 (cancer or tumo#r))

S3 (MH "Leukemia+")

S4 (MH "Posterior Fossa Syndrome")


S5 (MH "Communication+")

S6 (MH "Communicative Disorders+")

S7 ((speech or articul* or stutter* or voice or vocal) N3 (disorder* or impair* or problem* or difficult* or outcome* or skill*))

S8 ((phonat* or prosod* or intonat*) N3 (disorder* or impair* or problem* or difficult* or outcome* or skill*))

S9 ((language or phonolog* or syntax or syntactic or gramma* or semantic* or pragmatic*) N3 (disorder* or impair* or problem* or difficult* or outcome* or skill*))



S10 (social N2 (skill* or language))

S11 discourse

S12 (literacy N3 (disorder* or impair* or problem* or difficult* or outcome* or skill*))

S13 pre#litera*

S14 phon* N1 aware*

S15 (MH "Neuropsychology")

S16 (MH "Voice Disorders+")

S17 neurocogniti*

S18 (MH "Deglutition Disorders")

S19 dysphagia

S20 ((swallow* or deglutition) N5 (abnormal* or difficult* or disorder* or dysfunc* or func* or impair* or outcome* or skill*))

S21 (MH "Academic Performance+")

S22 S1 OR S2 OR S3 OR S4

S23 S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21

S24 S22 AND S23

Refine Results to: Source type: Academic Journals, Age: All child, Publication date: 1988 - 2018



Web of Science

Platform: Clarivate Analytics

Date completed: 15th June, 2018 (re-run 21st August, 2019)

TOPIC: ((((((brain or "central nervous system" or "posterior fossa" or "primitive neuroectodermal" or cerebellar or *tentorial or brainstem) and (tumor or tumour or cancer)) or astrocytoma or medulloblastoma or ependymoma or leukaemia or leukemia or "acute lymphoblastic leukaemia" or "acute lymphoblastic leukemia" or "posterior fossa syndrome" or "cerebellar mutism")))) AND TOPIC: ((((((literacy or speech or articulation or voice or vocal or phonation or prosody or intonation or stuttering or cluttering or stammering or fluency or communication or language or phonolog* or synta* or grammar* or semantic* or pragmatic* or swallow* or deglutition) and (disorder* or impair* or difficult* or problem* or outcome* or skill* or abnormal* or *func*)) or "speech intelligibility" or "speech rate" or dysarthria or dyspraxia or apraxia or mutism or "cerebellar mutism" or "posterior fossa syndrome" or "childhood apraxia of speech" or "social skill*" or "social language" or narrative* or discourse or conversation* or *phasia or literacy or dyslexia or pre-litera* or prelitera* or "phon* aware*" or neuropsych* or neurocogniti* or "verbal learning" or "verbal fluency" or "verbal memory" or naming or dysphagia or "Academic achievement*")))) AND TOPIC: (((bab* or infant* or newborn* or neonate* or toddler* or preschool* or pre-school* or child* or school-age* or schoolchild* or adolescen* or teen* or juvenile* or "young people*" or "young person*" or youth* or paediatric or pediatric)))

Refined by: DOCUMENT TYPES: (ARTICLE OR REVIEW OR EARLY ACCESS)

Timespan: 1988-2018. Indexes: SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI, CCR-EXPANDED, IC.

