



THE UNIVERSITY OF  
SYDNEY



NEUROKIDS  
COMMUNICATION  
RESEARCH  
LABORATORY

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



Images/graphics in mock-up form only

## Guideline

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# Glossary

Term	Definition
Childhood brain tumour	A brain tumour in childhood is an abnormal mass of cells growing in the brain. It can be malignant or benign (not malignant). It can start to grow before birth in the foetal period, or anytime during childhood. Tumours can grow slowly over time, causing a slow onset of symptoms, or quickly with a faster onset of more obvious symptoms. Brain tumours can be treated with a combination of surgery, radiotherapy and/or chemotherapy, depending on the type. There are no clear known causes.
Communication	Communication includes speech, language, voice, and fluency skills.
Dysphagia	A swallowing disorder that occurs when there is a breakdown of the oral, pharyngeal, and/or oesophageal phases, which can also result in significant weight loss, inadequate growth, or negatively impact on development
Evidence to Decision (EtD) Framework	The GRADE Evidence to Decision (EtD) Framework provides a structured way to combine research findings with other key factors to develop guidelines and make clinical recommendations. It helps to guide decision makers through a set of criteria, ensuring that each criterion is considered equally, and decisions are transparently reported.
Fluency	Fluency is the rhythm and flow of speech.
GRADE	GRADE (Grading of Recommendations, Assessment, Development and Evaluation) is used to rate the certainty or quality of a body of evidence. Each outcome area is given a rating from high to very low.
Language	Language is the comprehension and production of words, sentences, and texts for communication. This includes vocabulary (e.g. the store of words that an individual understands and uses), grammar/syntax (e.g. the way words are combined into phrases and sentences to form meaning), discourse (e.g. written language and text-level), social communication (e.g. skills needed to manage a conversation successfully, such as turn-taking, staying on topic, inferencing, ambiguity, jokes and metaphors) and literacy (e.g. reading, spelling and writing). Language can occur in many modalities, such as spoken, written and alternative augmentative domains (e.g. sign language, communication devices).

Leukaemia	Leukaemia is a cancer of the white blood cells, where more leukocytes (or immature white blood cells) are produced and suppress normal blood cells. If leukaemia is diagnosed as acute, the disease progresses more quickly and requires more aggressive treatment. Treatments can include monitoring, chemotherapy, radiotherapy, and/or stem-cell transplant.
Quality of Life	Quality of life refers to an individual's ability to participate based on functional outcomes. Quality of life is often considered alongside quantity (or duration) of life.
Speech	Speech is the production of speech sounds in words. It involves both articulation/ motor speech production and linguistic skills (e.g. sounds, intonation, stress, prosody).
Swallowing	Swallowing includes feeding behaviours that occur when eating or drinking (e.g. sensory responses to food, opening the mouth, chewing, and moving food or liquid around the mouth).
Voice	Voice is the coordination of respiration, phonation and resonance.

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# Abbreviations

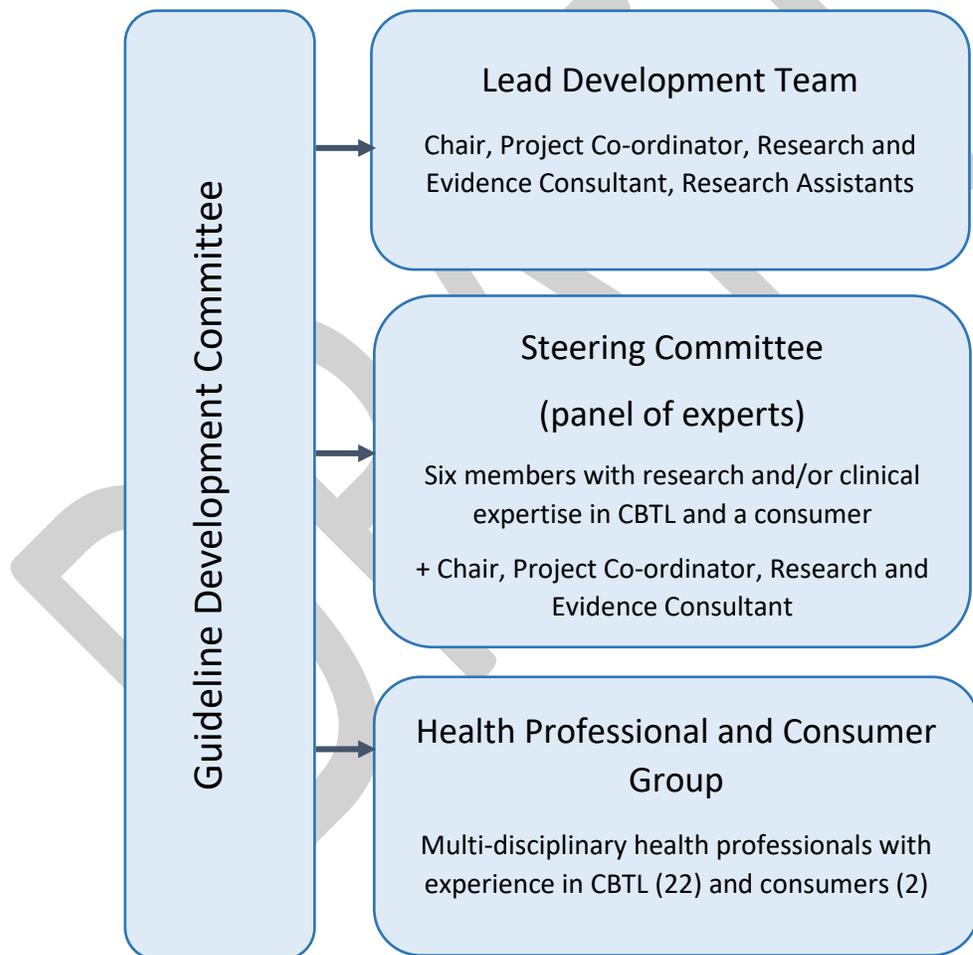
Acronym	Expansion
AGREE II	Appraisal of Guidelines for Research and Evaluation II
ALL	Acute Lymphoblastic Leukaemia
AML	Acute Myeloid Leukaemia
ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and Linguistically Diverse
CBTL	Childhood Brain Tumour or Leukaemia
CNS	Central Nervous System
EtD	Evidence to Decision
GRADE	Grading of Recommendations, Assessment, Development and Evaluation
pCMS/CMS	Postoperative Cerebellar Mutism Syndrome/ Cerebellar Mutism Syndrome
PFS	Posterior Fossa Syndrome

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# Guideline Development Committee

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 shown in Figure 1 and the specific roles and responsibilities of each member/group are detailed in the following sections. Table 1 includes all members of the Guideline Development Committee detailing name and organisation, discipline, role in the Guideline development process and experience with childhood brain tumour and/or leukaemia.

Figure 1: Guideline Development Committee



CBTL = Childhood brain tumour or leukaemia

# Committee Roles

## Chair

The Chair, Dr Kimberley Docking, is an experienced Speech Pathologist and researcher with over 20 years of experience in the area of CBTL. The Chair was responsible for:

- Obtaining and managing funding and reporting to the funding body throughout the Guideline process;
- Conceptualisation of the Guideline;
- Registering the Guideline with NHMRC and developing NHMRC timeline documentation;
- Employment of paid team members working on the project;
- Inviting and engaging the Steering Committee;
- Liaising with key stakeholders, including major national children's hospitals throughout the Guideline process;
- Development of the clinical questions to be addressed in the Guideline in consultation with the Project Co-ordinator and Steering Committee;
- Systematic review screening, data extraction and appraisal in conjunction with Project Co-ordinator and Research Assistant team;
- Conducting appropriate methodology for rating the quality of evidence and strength of recommendations in conjunction with Research and Evidence Consultant, Project Co-ordinator, and Research Assistant team;
- Recruitment of a Health Professional and Consumer Group, including consumer members, in conjunction with Project Co-ordinator;
- Development of health professional and consumer survey in conjunction with Project Co-ordinator and Research Assistants, Ms Sara Chami and Ms Emma Campbell;
- Ethics application for health professional and consumer survey in conjunction with Project Co-ordinator and Research Assistant, Ms Sara Chami;
- Data analysis methods for health professional and consumer survey in conjunction with Project Co-ordinator and Research Assistant, Ms Sara Chami;
- Liaising with the Project Co-ordinator and Research and Evidence Consultant to complete the GRADE Evidence-to-Decision Framework processes;
- Providing input as a member of the Steering Committee via completion of the GRADE Evidence-to-Decision Framework;

- Development of evidence-based recommendations in conjunction with Project Co-ordinator and the Steering Committee;
- Development of the Guideline, Technical and Administrative report and other associated documents in conjunction with the Project Co-ordinator and Research and Evidence Consultant;
- Development of the Dissemination Plan;
- Organising public consultation; inviting key national and international stakeholder organisations to comment, liaising with organisations;
- Nominating independent expert reviewers;
- Working with NHMRC to ensure all Guideline requirements met in conjunction with the Project Co-ordinator.

### Project Co-ordinator

The Project Co-ordinator, Dr Rosemary Hodges, is an experienced paediatric Speech Pathologist and researcher. She was responsible for:

- Coordination of the Guideline project and team members;
- Development of the clinical questions to be addressed in the Guideline in consultation with Chair and Steering Committee;
- Systematic search of the literature evidence;
- Systematic review screening, data extraction and appraisal in conjunction with Chair and Research Assistants;
- Creating summary of individual study evidence tables, GRADE summary of findings tables and GRADE Evidence-to-Decision tables with guidance from Research and Evidence Consultant;
- Conducting appropriate methodology for rating the quality of evidence and strength of recommendations in conjunction with Research and Evidence Consultant, Chair, and Research Assistants;
- Recruitment of a Health Professional and Consumer Group in conjunction with Chair;
- Development of health professional and consumer survey in conjunction with Chair and Research Assistants, Ms Sara Chami and Ms Emma Campbell;
- Ethics application for health professional and consumer survey in conjunction with Chair and Research Assistant, Ms Sara Chami;
- Data analysis methods for health professional and consumer survey in conjunction with Chair and Research Assistant, Ms Sara Chami;

- Development of Declarations of Interest form, collecting and collating declarations of interests from all team members;
- Collating the evidence from the systematic review and presenting to the Steering Committee in accessible way to allow completion of the GRADE Evidence-to-Decision Framework in conjunction with Research and Evidence Consultant;
- Providing input as a member of the Steering Committee via completion of the GRADE Evidence-to-Decision Framework;
- Development of evidence-based recommendations in conjunction with the Steering Committee and Chair;
- Development of the Guideline, Administrative and Technical Report in conjunction with Research and Evidence Consultant and Chair;
- Working with NHMRC to ensure all Guideline requirements met in conjunction with Chair.

#### Research and Evidence Consultant

Dr Lani Campbell is an experienced Speech Pathologist and Researcher and Evidence Consultant. She provided specific methodological input into the GRADE certainty of the evidence ratings and GRADE Evidence-to-Decision Frameworks. She was responsible for:

- Providing guidance on the use of the Grading of Recommendations Assessment, Development and Evaluation (GRADE; <http://www.gradeworkinggroup.org/>) approach to rating the certainty of the evidence;
- Consulting with key GRADE methodologists about the project;
- Developing templates and guidance on completing individual study summary tables, GRADE Summary of Findings tables and GRADE Evidence-to-Decision tables;
- Collating the evidence from the systematic review and presenting to the Steering Committee in accessible way to allow completion of the GRADE Evidence-to-Decision Framework in conjunction with Project Co-ordinator;
- Providing input as a member of the Steering Committee via completion of the GRADE Evidence-to-Decision Framework;
- Contributing to the structure and content of the Administrative and Technical Report in consultation with the Project Co-ordinator;
- Contributing knowledge translation content in Guideline document;
- Contributing to Dissemination Plan.

### Research Assistant team

The Lead Development team also included two Research Assistants (Ms Sara Chami, Ms Emma Campbell) and an honorary Research Affiliate (Ms Stefani Ribeiro Knijnik). All are qualified and experienced Speech Pathologists with research experience and training at either Honours or Research Masters level. Their roles included:

- Contributing to content of the health professional and consumer survey and creation of the survey on Qualtrics platform;
- Preparation of ethics application documents for the health professional and consumer survey, in consultation with Chair and Project Co-ordinator;
- Developing data extraction forms and spreadsheets for systematic review in consultation with Project Co-ordinator;
- Data extraction for systematic review;
- Completing JBI appraisal checklists for systematic review;
- Data entry and analysis for the health professional and consumer survey;
- Referencing and formatting support for Guideline documents;
- Providing input to draft Guideline documents.

### Steering Committee (panel of experts)

The Steering Committee comprised six members (five clinical researchers and health professionals with expertise in Speech Pathology, Psychology, Neurolinguistics, Rehabilitation, and Oncology; and one consumer who is a parent of a child diagnosed with leukaemia) in addition to the Chair, Project Co-ordinator and Research and Evidence Consultant. Members of the Steering Committee were invited to the role by the Chair or through a call for interest via ANZCHOG (Australian and New Zealand Childrens Haematology/Oncology Group). The rationale for the Guideline and roles/responsibilities of Steering Committee members were provided by the Chair and discussed when each individual was invited.

The Steering Committee's role was to provide input and feedback across all phases of Guideline development including clinical question development, systematic review, survey development, evidence synthesis and development of the recommendations (please note: the consumer member of the Steering Committee joined prior to the presentation of the evidence synthesis, and contributed to the development of recommendations).

### Health Professional and Consumer Group

The Health Professional and Consumer Group included 22 multi-disciplinary health professionals with experience in CBTL and two consumers (parents of children diagnosed with CBTL). The role of Health

Professional and Consumer Group members was to complete an online survey to gather their perspectives and input into the clinical management of communication and swallowing in children diagnosed with CBTL.

#### Consumer perspectives and involvement

Consumer involvement was integral to the development of this Guideline. A consumer representative was a member of the Steering Committee. She is the mother of a child diagnosed with leukaemia. Her perspectives and input were invaluable in the process of the GRADE Evidence-to-Decision frameworks and the development of recommendations. Two consumers provided input as members of the Health Professional and Consumer Group, both mothers of children diagnosed with brain tumour. They provided input via a health professional and consumer survey.

#### Participation and representation of Aboriginal and Torres Strait Islander people and Culturally and Linguistically Diverse groups

The Guideline Development Committee membership comprised one member who is an Aboriginal and Torres Strait Islander person as well as numerous culturally and linguistically diverse (CALD) members. A total of 38% of the Guideline Development Committee chose to identify as either an Aboriginal and Torres Strait Islander person or CALD group.

Table 1. Guideline Development Committee Members

Name and Organisation	Role in Guideline	Discipline	Experience with CBTL
Dr Kimberley Docking <i>The University of Sydney</i>	Chair	Speech Pathology	Leader of research lab focused on communication and swallowing in children diagnosed with CBTL; 20 years clinical and research experience in CBTL as a researcher and speech pathologist
Dr Rosemary Hodges <i>The University of Sydney</i>	Project Co-coordinator	Speech Pathology	Speech Pathologist with 10 years clinical and research experience in paediatrics and researcher in area of CBTL for over 3 years
Dr Lani Campbell <i>The University of Sydney</i>	Research and Evidence Consultant	Speech Pathology	Speech Pathologist and researcher in CBTL for 18 months
Ms Sara Chami <i>The University of Sydney</i>	Research Assistant	Speech Pathology	Speech Pathologist and researcher in area of CBTL for over 2 years
Ms Stefani Ribeiro Knijnik <i>The University of Sydney</i>	Research Assistant	Speech Pathology	Speech Pathologist experience in infants and children with dysphagia as a result of CBTL; researcher in CBTL for 1 year
Ms Emma Campbell <i>The University of Sydney; Western Sydney Local Health District</i>	Research Assistant	Speech Pathology	Researcher in CBTL for 2 years
Professor Angela Morgan <i>Murdoch Children's Research Institute; University of Melbourne</i>	Steering Committee	Speech Pathology	20 years of clinical and research work in paediatric Speech Pathology, including CBTL
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	Psychology	Leader of Australasia's largest paediatric psycho-oncology research group; researcher with focus on patient/family needs in childhood cancer, including CBTL

Professor Philippe Paquier <i>Vrije Universiteit Brussel (VUB) &amp; Université Libre de Bruxelles (ULB)</i>	Steering Committee	Neurolinguistics	Researcher with focus on paediatric neurocognitive and speech/language disorders, including special interests in; cerebellar mutism syndrome and the long-term neurocognitive outcomes of childhood brain tumour survivors
Dr Luciano Dalla-Pozza <i>The Cancer Centre for Children, The Children's Hospital at Westmead</i>	Steering Committee	Oncology	Director of major metropolitan paediatric cancer centre; provision of primary care and follow-up
Dr Mary-Clare Waugh <i>The Children's Hospital at Westmead, The University of Sydney Medical School</i>	Steering Committee	Rehabilitation	Over 20 years experience working with children with congenital and acquired brain and/or spinal cord lesions resulting in dysphagia and communication difficulties; Extensive experience working in large multidisciplinary teams with rehabilitation goal directed interventions
Ms Maria Messina <i>Consumer</i>	Steering Committee	Consumer & Educator	Mother of child diagnosed with leukaemia
Ms Claire Radford <i>Queensland Children's Hospital</i>	Health Professional and Consumer Group	Speech Pathology	5 years experience as senior speech pathologist and allied health team leader (oncology and palliative care). Previously, 6 years clinical experience treating children with acquired brain injury including children with CBTL
Ms Brooke Spencer <i>Queensland Children's Hospital</i>	Health Professional and Consumer Group	Oncology Nursing	25 years paediatric oncology nursing with the last 4 years in neuro-oncology clinical nurse consultant role
Ms Hayley Coulson <i>Queensland Children's Hospital</i>	Health Professional and Consumer Group	Physiotherapy	5 years experience as senior oncology physiotherapist in paediatric setting
Dr Cinzia De Luca <i>The Royal Children's Hospital, Melbourne</i>	Health Professional and Consumer Group	Neuropsychology	Co-ordinator of the neuropsychology service at major metropolitan children's hospital
Ms Candice Brady <i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network</i>	Health Professional and Consumer Group	Speech Pathology	Speech Pathologist providing services to children post- tumour resection /oncology care

Ms Suzi Drevensek <i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network</i>	Health Professional and Consumer Group	Speech Pathology	Speech Pathologist providing services to children who have acquired brain injury associated with brain tumour
Dr Robyn Stargatt <i>La Trobe University</i>	Health Professional and Consumer Group	Neuropsychology	30 years experience in clinical work and research in public and private sector with children diagnosed with CBTL
Ms Amanda Simon <i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network</i>	Health Professional and Consumer Group	Speech Pathology	Assessment and management of children with CBTL who have swallowing difficulties
Ms Kate Osland <i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network</i>	Health Professional and Consumer Group	Speech Pathology	7 years experience providing inpatient and outpatient assessment and therapy to children with CBTL
Ms Gloria Tzannes <i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network</i>	Health Professional and Consumer Group	Speech Pathology	Assessment and management of children with CBTL who present with swallowing difficulties and communication disorders; contributes at governance level model of care within major metropolitan children's hospital
Ms Melissa Parkin <i>Sydney Children's Hospital Randwick, Sydney Children's Hospitals Network</i>	Health Professional and Consumer Group	Speech Pathology	Acute and chronic feeding and swallowing disorders in children with CBTL
Dr Jennifer Cohen <i>Discipline of Paediatrics, School of Women's and Children's Health, University of NSW</i>	Health Professional and Consumer Group	Dietetics	15 years experience as clinical dietitian providing nutritional support for families and children being treated for childhood cancer, including CBTL; researcher with focus on nutritional management of childhood cancer patients and survivors
Dr Laura Janzen <i>The Hospital for Sick Children, Toronto</i>	Health Professional and Consumer Group	Neuropsychology	12 years experience providing clinical neuropsychology assessment and consultation services to the neuro-oncology and leukemia programs major metropolitan children's hospital; researcher in neuro-oncology

Ms Jane Fong <i>Women's and Children's Hospital, Adelaide</i>	Health Professional and Consumer Group	Speech Pathology	Speech pathology assessment and therapy for children with brain tumour or spinal cord tumour
Ms Lauren Leeming <i>Sydney Children's Hospital Network</i>	Health Professional and Consumer Group	Speech Pathology	14 years experience working with paediatric feeding/swallowing difficulties within the acute hospital setting including the oncology/haematology caseload
Dr Amanda Lane-Brown <i>Sydney Children's Hospital Network</i>	Health Professional and Consumer Group	Psychology	Clinical psychologist working in inpatient rehabilitation team with children who are diagnosed with brain tumours
Ms Roxanne McLeod <i>Sydney Children's Hospital Network</i>	Health Professional and Consumer Group	Music Therapy	8.5 years experience providing music therapy to paediatric oncology patients and their families
Miriam Cromie <i>Child Life and Music Therapy, The Children's Hospital at Westmead</i>	Health Professional and Consumer Group	Music Therapy	12 years experience in paediatric oncology as both a music therapist and child life therapist
Geoff McCowage <i>The Children's Hospital at Westmead</i>	Health Professional and Consumer Group	Oncology	Paediatric oncologist in major metropolitan children's hospital, member of multidisciplinary teams for both neurological cancer (brain and spinal cord) and leukaemia
Eliza-Jane Potter <i>The Children's Hospital at Westmead</i>	Health Professional and Consumer Group	Nursing	Paediatric oncology nurse in major metropolitan children's hospital
Dr Sumanth Nagabushan <i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network; The University of Sydney</i>	Health Professional and Consumer Group	Oncology	In and outpatient management of children diagnosed CBTL including overseeing routine clinical care, organising chemo-radiotherapy, coordinating multidisciplinary care with tertiary and local healthcare agencies, and engaging in clinically relevant research

Jessica De Bolfo <i>The Royal Children's Hospital Melbourne</i>	Health Professional and Consumer Group	Speech Pathology	Provide inpatient and outpatient service to oncology patients
Marion Corbett <i>Consumer</i>	Health Professional and Consumer Group	Consumer	Mother of child diagnosed with brain tumour
Tracey Power <i>Consumer</i>	Health Professional and Consumer Group	Consumer	Mother of child diagnosed with brain tumour

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# Plain English Summary

Childhood brain tumour and leukaemia are the two most common types of cancers in children. Treatments for these cancers have improved dramatically in recent years and now a majority of children survive. However, these cancers and their treatments can have negative effects on child development, including communication and swallowing skills.

This guideline makes two main recommendations about the management of communication and swallowing difficulties in children diagnosed with childhood brain tumour or leukaemia as shown below.

## **Recommendation 1: Communication assessment and intervention should be offered to children diagnosed with childhood brain tumour or leukaemia**

The communication recommendation made in this Guideline calls for communication assessment and intervention to be offered to children diagnosed with brain tumour or leukaemia. This is needed because these children often experience communication difficulties such as problems with producing clear speech, understanding and using language, and literacy skills such as reading and writing. Communication difficulties may be seen at the time of cancer diagnosis or during cancer treatment but can also be seen months or years after cancer treatment.

## **Recommendation 2: Swallowing assessment and management should be offered to children diagnosed with childhood brain tumour or leukaemia**

The swallowing recommendation made in this Guideline calls for swallowing assessment and management to be offered to children diagnosed with brain tumour or leukaemia. This is needed because the ability to swallow foods and fluids can be compromised in these children. This can be life-threatening as it puts the child at-risk of chest infections if food/fluid enters the lungs. Swallowing difficulties are frequently reported during cancer treatment. However, there is some evidence that swallowing difficulties may continue into the longer-term, once cancer treatment has finished.

# Executive Summary

## EVIDENCE-BASED RECOMMENDATION 1: COMMUNICATION

<b>Communication assessment and intervention should be offered to children diagnosed with childhood brain tumour or leukaemia</b>	Strong Recommendation <sup>a</sup>
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### KEY PRACTICE POINTS

<b>Assessment &amp; Intervention</b>
<b><i>When to assess</i></b>
Communication assessment should occur at or as soon as possible after cancer diagnosis.
Communication assessment should occur during the oncology treatment phase and oncology follow-up phase. Multiple assessments during these phases may be required if concerns are indicated by the oncology care team and/or family.
Regular monitoring of the child's communication development should continue throughout the survivorship phase until end of adolescence.
<b><i>What to assess</i></b>
A comprehensive assessment of speech and language should be conducted. Assessment needs to be tailored to the age and developmental level of the child. Where appropriate, language assessment should include high-level language, discourse-level skills and literacy.
Assessment should include a range of individualised assessment procedures such as norm-referenced assessments, criterion-referenced tools, care-giver report and clinical observations across environments.
<b><i>When to intervene</i></b>
Children diagnosed with CBTL should be provided with early individualised intervention during the oncology treatment phase for identified communication difficulties.
Children diagnosed with CBTL should be provided with timely individualised intervention for communication difficulties identified during the oncology follow-up and survivorship phases through until the end of adolescence.
<b>Care Team</b>
Speech Pathologists should be involved as integral members of the oncology care team from the point of cancer diagnosis and throughout the oncology treatment and follow-up phases.
All members of the oncology care team should be informed about communication difficulties and involved in management throughout the oncology treatment and follow-up phases.
Speech Pathologists should work in partnership with oncologists, family members and education professionals to monitor communication development throughout the survivorship phase until the end of adolescence.
<b>Education</b>
Education about communication development and difficulties in CBTL should be provided to families at cancer diagnosis or as early as possible.
Education about communication development and difficulties in CBTL should continue to be provided to families throughout the oncology treatment and follow-up phases.
Education about potential long-term communication difficulties in CBTL should be provided to families and education professionals throughout the oncology follow-up and survivorship phases.

<sup>a</sup>Based on GRADE EtD framework

## EVIDENCE-BASED RECOMMENDATION 2: SWALLOWING

<b>Swallowing assessment and management should be offered to children diagnosed with childhood brain tumour or leukaemia</b>	Strong Recommendation <sup>a</sup>
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### KEY PRACTICE POINTS

<b>Assessment &amp; Intervention</b>
<b><i>When to assess</i></b>
Swallowing assessment should occur at or as soon as possible after diagnosis of CBTL.
Swallowing assessment should occur during the oncology treatment phase. Multiple assessments may be required where concerns are indicated by the oncology care team and/or family.
Regular monitoring of the child's swallowing should continue throughout the oncology follow-up and survivorship phases until end of adolescence.
<b><i>What to assess</i></b>
A comprehensive swallowing assessment should be conducted. Assessment needs to be tailored to the age and developmental level of the child. All phases of the swallow (pre-oral anticipatory, oral-preparatory, oral and pharyngeal) need to be assessed.
Videofluoroscopy should be considered on a case-by-case basis as part of the assessment protocol to examine aspiration.
<b><i>When to intervene</i></b>
Children diagnosed with CBTL should be provided with early individualised management for swallowing difficulties during the oncology treatment phase.
Children diagnosed with CBTL should be provided with individualised management for swallowing difficulties identified by the oncology care team and/or family in the oncology follow-up and survivorship phases.
<b>Care Team</b>
Speech Pathologists should be involved as integral members of the oncology care team from the point of cancer diagnosis and throughout the oncology treatment phase to manage swallowing.
All members of the oncology care team should be informed about swallowing difficulties and involved in their management as needed throughout oncology phases.
Speech Pathologists should work in partnership with oncologists and family members to monitor swallowing throughout the survivorship phase until the end of adolescence.
<b>Education</b>
Education about swallowing difficulties in CBTL should be provided to families at cancer diagnosis or as early as possible.
Education about swallowing difficulties in CBTL should continue to be provided to families throughout the oncology treatment and follow-up phases.

<sup>a</sup>Based on GRADE EtD framework

# Purpose & Scope

## Purpose

This Guideline was developed to address the need for a systematic, evidence-based approach to the management of communication and swallowing in children diagnosed with childhood brain tumour or leukaemia (CBTL). It aims to assist health professionals to provide and advocate for evidence-based care and management of communication and swallowing in children diagnosed with CBTL. It also aims to educate patient consumers (parents of children with CBTL, survivors of CBTL) and support them to advocate for best practice management of communication and swallowing difficulties.

The intended outcome of this Guideline is to improve quality of life for children surviving brain cancer and leukaemia. This has involved translating evidence from the research and clinical/consumer expertise into recommendations that will guide improvements in cancer services and quality of clinical care for this population across Australia and worldwide.

The implementation of the evidence-based recommendations presented here will result in a systematic and equitable approach to clinical management for communication and swallowing in CBTL, including long-term follow-up. This Guideline will also form the basis for targeted early intervention program development and survivorship surveillance planning. These recommendations will support children to keep healthy and lead a fulfilled life, not only during cancer diagnosis and treatment, but critically after cancer survival.

## Clinical problem

Child survivors of brain cancer and leukaemia - the top two most common childhood cancers in Australia and developed countries worldwide - often face a new challenge during and after their cancer treatment is completed.<sup>1-6</sup> While incidence rates continue to rise, so do survival rates and the size of this rapidly growing population of survivors, due to advancements in medical care and treatments.<sup>3,6-8</sup> Effects from the cancer and treatments can have significant and often severe impact to quality of life in the areas of communication and swallowing; affecting a child or adolescent's development of new skills, their ability to communicate their needs, succeed at school, make friends, engage in family mealtimes or eat-out socially, use social media, successfully date, or achieve social and financial independence in adulthood.<sup>9</sup>

To date, an equitable and systematic approach to management for communication and swallowing has not been established in Australia or worldwide; despite children diagnosed with CBTL remaining at-risk throughout development and into adulthood if untreated or lost to follow-up.

### 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.<sup>10</sup> The clinical questions are shown in the box below:

Box A. Clinical questions used to develop this guideline

Communication Outcomes	<i>What are the communication outcomes associated with childhood brain tumour or leukaemia?</i>
Swallowing Outcomes	<i>What are the swallowing outcomes associated with childhood brain tumour or leukaemia?</i>

### The population

The Guideline focuses on children diagnosed with any type of childhood brain tumour or leukaemia aged 0-16 years of age.

#### Brain tumour or leukaemia

A brain tumour in childhood is an abnormal mass of cells growing in the brain. It can be malignant or benign (not malignant). Tumours can start to grow before birth in the foetal period, or anytime during childhood. They can grow slowly over time, causing a slow onset of symptoms, or quickly with a faster onset of more obvious symptoms. Brain tumours can be treated with a combination of surgery, radiotherapy and/or chemotherapy, depending on the type and malignancy. There are no clear known causes.

Leukaemia is a cancer of the white blood cells, where more leukocytes (or immature white blood cells) are produced and suppress normal blood cells. If leukaemia is diagnosed as acute, the disease progresses more quickly and requires more aggressive treatment. Treatments can include monitoring, chemotherapy, radiotherapy, and/or stem-cell transplant.

The population of CBTL is inherently diverse, due to a range of presentation characteristics. Examples of diversity include differences in cancer diagnoses, cancer treatments, cancer treatment effects (during and after), age at diagnosis, as well as progression of disease, periods of admission, medical complications (e.g. increased intracranial pressure, infections), family circumstances and values.

In this Guideline, brain tumour and leukaemia have been considered as one population (i.e. childhood brain tumour or leukaemia; CBTL) due to the similarities in central nervous system (CNS) targeted cancer treatments and outcomes for these groups. Both cancer groups often receive CNS applied chemotherapy and/or radiotherapy that are reported to impact the developing brain and CNS.<sup>4</sup> However, a majority of the literature evidence on which the Guideline recommendations are based was noted to be more largely represented by reports of children with brain tumour (see Administrative & Technical Report, p. 21), with a relatively recent increase in the amount of leukaemia studies.

### Age

The scope of the Guideline focuses on children aged 0-16 years. The 16-year age limit represents the upper age limit commonly applied to patients receiving paediatric services in the majority of Australian hospitals/cancer centres. The current available evidence base does not support further sub-grouping of recommendations into separate age groups. However, the key practice points presented in this guideline about assessment consider age of the child to ensure that age-appropriate assessment procedures are applied. It is, however, anticipated that survivorship experiences will extend beyond this age group into upper adolescence and early adulthood. The Guideline discusses the implications for future application and services throughout survivorship and into adulthood for child survivors.

### Timing and setting in childhood brain tumour or leukaemia: A framework

Even after cancer diagnosis and treatment, children with CBTL face a long road ahead, with regular monitoring of their medical and cancer status. This is necessary due to risk of cancer recurrence for some cancer types.<sup>11,12</sup> It is also important because of the potential ongoing impact of the cancer and its treatment on health and development.<sup>13-19</sup>

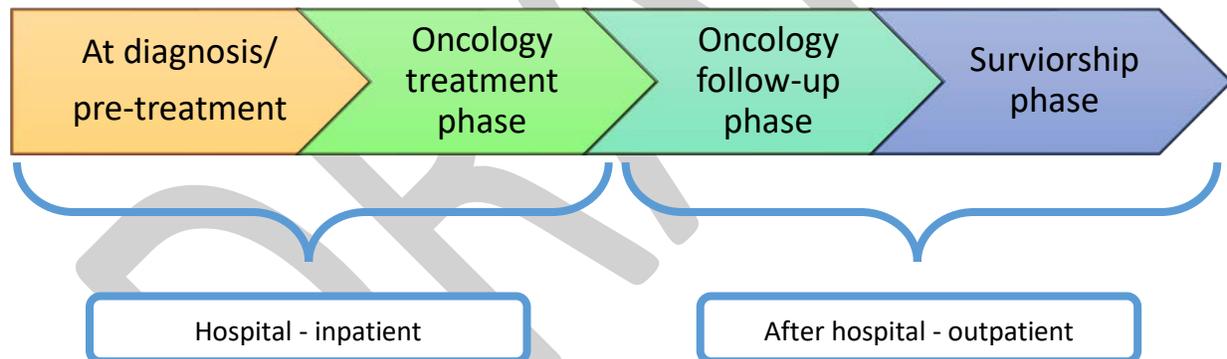
Therefore, the course of CBTL needs to be conceptualised over time, as well as adopting a long-term approach to health and well-being. Literature focusing on communication and swallowing skills in this population have examined outcomes at one or more points in time across a child's cancer journey, from diagnosis through to survivorship. To provide consistency in describing these time points, the authors of this Guideline have developed a framework (see Figure 2). This framework identifies four key paediatric oncology phases:

- 1) At diagnosis/pre-treatment: at cancer diagnosis, prior to the start of cancer treatment
- 2) Oncology treatment phase: during or, in the weeks after, cancer treatment
- 3) Oncology follow-up phase: <5 years since cancer treatment has finished
- 4) Survivorship phase  $\geq$ 5 years since cancer treatment has finished

These oncology phases are closely linked with setting. While some studies examine outcomes while children diagnosed with CBTL are still in hospital, others do so in community settings such as clinics, schools and at home. For simplicity, in the framework, setting has been binary classified into: “hospital - inpatient” and “after hospital - outpatient”.

It is important to recognise that due to the possibility of cancer recurrence, secondary cancer/s, or multiple primary cancer/s, a child may return to an earlier phase in this framework. For example, a child who is cancer-free for six years and considered to be in the survivorship phase may experience cancer recurrence and therefore return to oncology treatment phase.

Figure 2. Framework of timing and setting in childhood brain tumour/leukaemia



### Intended end users of the Guideline

This Guideline has been developed to provide evidence-based recommendations for Speech Pathologists and multidisciplinary health professionals involved in the management of communication and swallowing difficulties for children diagnosed with childhood brain tumour or leukaemia. It is to be used alongside clinician judgement and patient preferences. It is based on the best evidence available at the time of publication. Additional relevant health professionals may include, but are not limited to, Oncologists, Rehabilitation Physicians, Nurses, Occupational Therapists, Physiotherapists, Child Life and Music Therapists. It is also intended that education providers in educational settings will also access the

Guideline and recommendations in order to support CBTL survivors to transition back into the classroom and school community for educational services.

These recommendations will equip parents and families as lifelong advocates in seeking optimal quality of life outcomes for their children, by providing knowledge about issues their child may likely experience and what these might look like. This will ensure families can be connected with timely management, early intervention services and appropriate referral services. It is important that parents do not feel isolated or lost to follow-up, or do not feel inadequately prepared for their child's future.<sup>20</sup> This cohesive source of information about long-term communication and swallowing management will serve to guide survivors and their families to partner with health professionals where necessary to ensure improved quality of life outcomes for communication and swallowing.

### Cultural considerations

Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse (CALD) communities as well as families from socio-economically disadvantaged backgrounds face unique challenges in regard to accessing cancer care services. A rapid review commissioned by the Cancer Institute NSW<sup>17</sup> highlighted the importance of practical, educational and social support in improving cancer outcomes and achieving increased satisfaction for CALD populations. This review specified that the development of culturally appropriate interventions and programs should consider individual and cultural barriers to accessing health services.<sup>17</sup> A lower prevalence has recently been reported for admissions of children with chronic conditions from socio-economically disadvantaged or regional and remote areas, including cancer diagnoses.<sup>9</sup> This has been attributed to reduced access to hospital services due to location, as well as cultural barriers for some population groups.<sup>9</sup> However, presentation of children from these areas were more highly represented in emergency admission rates, suggesting that visits were less likely to be planned.<sup>9</sup>

Australians now come from nearly 200 countries and represent more than 300 ancestries.<sup>21-23</sup> Based on the most recent available Australian census data in 2016, 3.3% of the total Australian population is represented by Aboriginal and Torres Strait Islander people (798,400).<sup>24</sup> One in four people in Australia (26%) are born overseas with over 300 separately identified languages spoken at home.<sup>21-23</sup> While English is the main language spoken, the most recent population data reports that 21% of Australians speak a language other than English at home.<sup>21</sup> For example, the most commonly spoken language in Sydney is Arabic (4.8% of the total population), closely followed by Mandarin (3.6%), Cantonese (3.5%), Vietnamese

(2.3%), Greek (2.1%), and Italian (2.1%). Of the overseas-born people who had arrived in the 25 years prior to 2016, 11% either did not speak English well or at all.<sup>21</sup>

In these Guidelines, the cultural diversity of Australians was considered in several ways. In the systematic review of evidence that informed development of the recommendations, the search strategy for the population concept was purposefully broad (i.e., brain cancer or leukaemia AND child) so as to capture studies across all potential population/cultural subgroups (see Administrative and Technical report, p. 16). Many studies in the systematic review, however, were found to focus on English-only language speakers and noted to be an eligibility criterion of most reported studies.

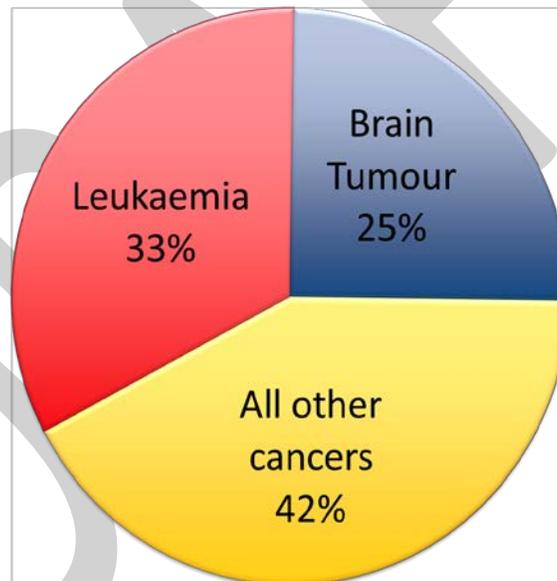
Issues relevant to Aboriginal and Torres Strait Islander people and CALD populations were also considered through the evidence from the Health Professional and Consumer Group and Steering Committee members. Several members identified as CALD and/or currently work directly with clinical populations. They incorporated their experience and knowledge of Aboriginal and Torres Strait Islander people and CALD families when providing their input. Important considerations for implementation of the Guideline for Aboriginal and Torres Strait Islander people and CALD populations can be found in the Dissemination Plan.

# Background

## Incidence of childhood brain tumour/leukaemia

Childhood brain tumour and leukaemia are the leading forms of cancer in children in Australia and developed countries worldwide.<sup>1,2,5,6,25</sup> Leukaemia is frequently reported as the most common cancer in children, representing approximately one-third of all diagnosed cancers<sup>6,8</sup> (see Figure 3). This is closely followed by brain tumours, the most common of all solid tumours in children. Brain tumours are commonly reported to represent one-quarter of all cancers in children in Australia.<sup>1-3,6,8</sup> In Australia, approximately 240 children are diagnosed with leukaemia every year, and 192 with brain tumour.<sup>6</sup> Forty-five percent of new cases of childhood brain tumour are in young children aged 0–4 years.<sup>26</sup> In the US, brain and other CNS cancers are more common than leukaemia in children in the 0-14 year age group.<sup>5</sup>

Figure 3: Incidence of childhood cancers<sup>1,3,6,8</sup>



Presentation, histology, and diagnosis of a brain tumour or leukaemia in childhood provides important insight into the progression, incidence, location, accompanying symptoms and complications, malignancy, and the treatments required to halt, remove, or cure it. The most common brain tumour type in children is widely reported to be the astrocytoma with an incidence rate of 30-50%.<sup>27</sup> The five-year survival rate for astrocytomas is reported to be 84%.<sup>8</sup> Most prevalent is the juvenile pilocytic astrocytoma, which is a benign solid tumour currently with a ten-year survival rate of 96%.<sup>12,28-34</sup> This brain tumour type commonly

arises in the posterior fossa region in the brain, which includes the cerebellum, brain stem, and fourth ventricle. Sixty percent of all childhood brain tumours are located in the posterior fossa.<sup>12,30-33</sup> Males are more likely to develop an astrocytoma compared to females.<sup>32</sup> The next most frequently occurring brain tumour types in children are the medulloblastoma and the ependymoma; both malignant tumours with an incidence of 15-20 and 5-15% respectively.<sup>32,33,35,36</sup> Five-year survival rates for medulloblastomas have been reported at 69%,<sup>7</sup> and 72% for ependymomas.<sup>8</sup> A slight male predominance is reported for both malignant types.<sup>4,8</sup> Other common brain tumour types include craniopharyngiomas (4-7%), followed by supratentorial primitive neuroectodermal tumours (PNETs), visual pathway gliomas, choroid plexus tumours, pineal area tumours, and brainstem tumours.<sup>11,32,33</sup>

The most common leukaemia type in children is acute lymphoblastic leukaemia (ALL), accounting for more than 78% of diagnoses, followed by acute myeloid leukaemia (AML) at 16%.<sup>27,37-39</sup> Children diagnosed with ALL have a higher five-year survival rate of 93%, with 76% for acute myeloid leukaemia.<sup>8</sup> Survival rates are similar across both genders.<sup>8</sup>

The occurrence of CBTL in children shows wide diversity. For example, tissue origin for brain tumours, location within the central nervous system (CNS), and natural history in terms of growth rate and tumour dissemination<sup>40</sup>. Resulting effects of CBTL are also greatly influenced by the age of the child at presentation. In particular, children aged less than 3 years of age at the time of CNS cancer treatment are considered to be at greatest risk for late effects due to the immature stage of their brain development<sup>4</sup>. Inherently, a great challenge exists in the management of CBTL in regard to the developing brain, in addition to a need to respect the long-term function of the CNS.<sup>4,41,42</sup>

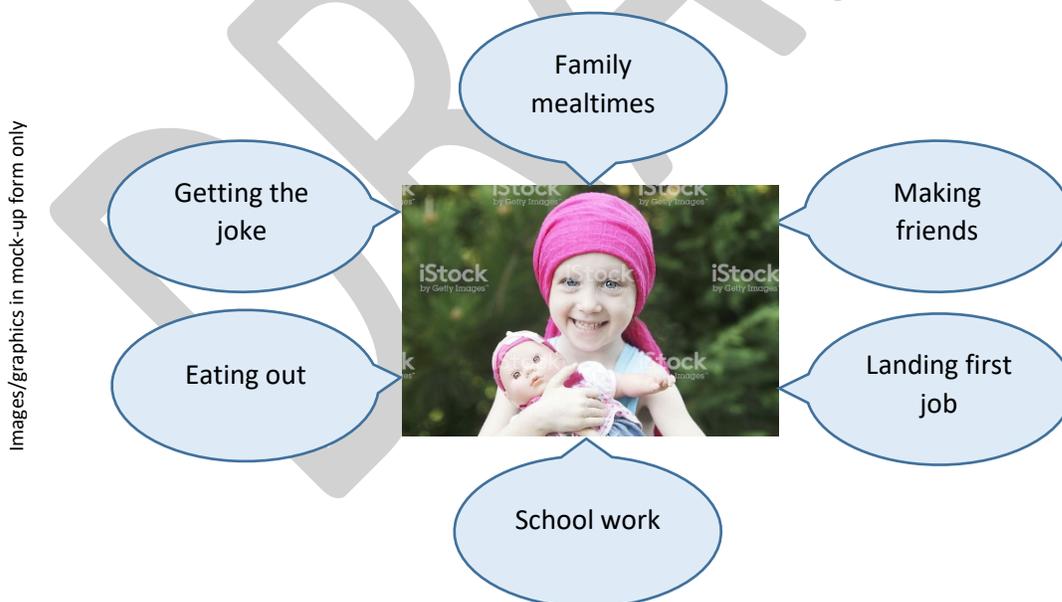
Time to diagnosis rates are also one of the difficulties associated with paediatric diagnoses. This includes issues with early detection and accurate acknowledgement of early generalised, non-specific symptoms and insidious onset.<sup>43-45</sup> Increased detection rates and more widely adopted and routinely administered diagnostic imaging practices have contributed to increases in incidence rates,<sup>31</sup> particularly those seen in Australia and other developed countries worldwide.

However, continual improvements in imaging, neurosurgical techniques, radiobiographical knowledge of CNS radiation tolerance, and advances in chemotherapy and implementation of CNS prophylaxis, have resulted in improved treatment strategies and survival rates for brain tumours and ALL.<sup>4,14,38-42,46,47</sup> Additionally, late sequelae that can occur as a result of treatment for CBTL is now routinely recognised, with effects on cognitive, neuroendocrine, and neuropsychological systems being evaluated critically and minimised where possible.<sup>4</sup>

## Impact of childhood brain tumour/leukaemia on communication and swallowing

While cancer treatment is essential for survival, the developing brain is extremely fragile and susceptible to the effects of treatment required to treat brain cancer and leukaemia.<sup>48,49</sup> In fact, many effects resulting from CNS-targeted treatment are not realised until many years later,<sup>29,50-53</sup> with persistent impact on subsequent development and communication skills in particular, due to late-occurring structural and functional changes in the brain.<sup>38,54,55</sup> These changes are progressive and often irreversible and can appear any time up to 10-20 years post-treatment, interrupting normal development in children who face the largest proportion of their lives post-survival.<sup>19,49</sup> Even though modern treatment protocols have changed over the decades to reduce negative effects from CNS targeted treatments, such as phasing out the use of cranial radiotherapy for ALL and adopting CNS-targeted chemotherapy, not all negative treatment effects have been avoided.<sup>18,38</sup>

Children diagnosed with CBTL are at risk of a range of communication difficulties, from difficulties with producing clear speech, to understanding instructions, using vocabulary, producing sentences and grammar, and reading and writing.<sup>29,38,50,56-62</sup> Children who are treated surgically for a brain tumour in the cerebellum are also at-risk of developing post-operative cerebellar mutism syndrome (pCMS), which involves a phase of mutism, or a total loss of speech, followed by speech and language difficulties.<sup>63-68</sup>



The impact of these communication difficulties on a child/adolescent's ability to participate in everyday life can be vast. They may find it harder to learn to talk as toddlers, tell stories, solve problems, make friends, understand jokes, succeed at school, get their first job and date. Survivors remain highly at-risk for developing communication difficulties well after cancer treatment is completed. Skills that are yet to

develop are most vulnerable, with these children failing to develop skills at the expected rate over time after CNS cancer treatment.<sup>19,55</sup> However, early intervention is known to minimise or prevent communication and swallowing difficulties that occur following treatment for childhood brain cancer or leukaemia if identified early.<sup>69-72</sup>

Children diagnosed with CBTL also commonly experience swallowing difficulties.<sup>73</sup> These difficulties may look like: trouble with chewing and biting, difficulty clearing food from the mouth effectively, difficulty with different food and fluid consistencies, fatiguing during eating, uncoordinated swallowing, or not coughing to bring up food. Swallowing difficulties frequently occur during oncology treatment, however, they may also exist into the longer-term.<sup>61,69</sup> Swallowing difficulties can have life-threatening impacts related to choking and chest infections.<sup>69</sup> Poor management of swallowing can lead to malnutrition and compromise development.<sup>73</sup> Swallowing difficulties also have significant participation impacts for these children/adolescents such as the ability to engage in family mealtimes and eat out with friends.

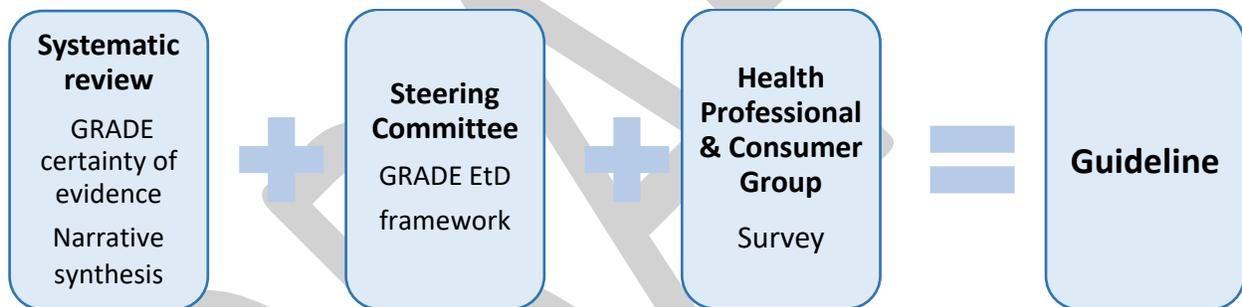
While this Guideline focuses on management in children, the impact of communication and swallowing difficulties on quality-of-life beyond childhood, adolescence into adulthood is also acknowledged for this population if they are not managed. Adult survivors of cancer may experience barriers to educational achievement as well as an impact to mental health, vocational independence and earning potential.<sup>9,74,75</sup> The long-term burden of CBTL can weigh on families, communities, and the health system, including costs that are associated with primary and ongoing healthcare services.<sup>9,74</sup>

# Evidence that Informed the Guideline

The two main recommendations presented in this Guideline are evidence-based. They have been informed by three sources of evidence as depicted in Figure 4:

- 1) Systematic review of the literature: GRADE Certainty of Evidence ratings and narrative synthesis methods were employed
- 2) Input from a Steering Committee comprised of research/clinical experts and a consumer via the GRADE Evidence-to-Decision (EtD) Framework
- 3) Input of a Health Professional and Consumer Group via a survey

Figure 4. Sources of evidence that were used to inform recommendations in this Guideline



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

# Communication Recommendation



Images/graphics in mock-up form only

## EVIDENCE-BASED RECOMMENDATION 1: COMMUNICATION

<b>Communication assessment and intervention should be offered to children diagnosed with childhood brain tumour or leukaemia</b>	Strong Recommendation <sup>a</sup>
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### KEY PRACTICE POINTS

<b>Assessment &amp; Intervention</b>
<b><i>When to assess</i></b>
Communication assessment should occur at or as soon as possible after cancer diagnosis.
Communication assessment should occur during the oncology treatment phase and oncology follow-up phase. Multiple assessments during these phases may be required if concerns are indicated by the oncology care team and/or family.
Regular monitoring of the child’s communication development should continue throughout the survivorship phase until end of adolescence.
<b><i>What to assess</i></b>
A comprehensive assessment of speech and language should be conducted. Assessment needs to be tailored to the age and developmental level of the child. Where appropriate, language assessment should include high-level language, discourse-level skills and literacy.
Assessment should include a range of individualised assessment procedures such as norm-referenced assessments, criterion-referenced tools, care-giver report and clinical observations across environments.
<b><i>When to intervene</i></b>
Children diagnosed with CBTL should be provided with early individualised intervention during the oncology treatment phase for identified communication difficulties.
Children diagnosed with CBTL should be provided with timely individualised intervention for communication difficulties identified during the oncology follow-up and survivorship phases through until the end of adolescence.
<b>Care Team</b>
Speech Pathologists should be involved as integral members of the oncology care team from the point of cancer diagnosis and throughout the oncology treatment and follow-up phases.
All members of the oncology care team should be informed about communication difficulties and involved in management throughout the oncology treatment and follow-up phases.
Speech Pathologists should work in partnership with oncologists, family members and education professionals to monitor communication development throughout the survivorship phase until the end of adolescence.
<b>Education</b>
Education about communication development and difficulties in CBTL should be provided to families at cancer diagnosis or as early as possible.
Education about communication development and difficulties in CBTL should continue to be provided to families throughout the oncology treatment and follow-up phases.
Education about potential long-term communication difficulties in CBTL should be provided to families and education professionals throughout the oncology follow-up and survivorship phases.

<sup>a</sup>Based on GRADE EtD framework

## Strength of communication recommendation

The strength of this recommendation was determined through the use of the GRADE Evidence-to-Decision (EtD) Framework. The EtD framework provided a structured approach to determine the strength of recommendation, integrating the systematic review findings with pre-specified criteria. The Steering Committee provided input throughout the process. Further detailed information about the EtD process and the complete EtD framework for communication can be found in the accompanying Administrative and Technical Report (p. 38-40, p. 41-51).

Based on the results of the GRADE EtD Framework, this recommendation was rated as strong. This means that the Steering Committee was confident that the desirable effects of adherence to the recommendation outweighed the undesirable effects. The implications of a strong recommendation for patients, clinicians and policy makers as identified by GRADE<sup>76</sup> are:

- *for patients — most people in your situation would want the recommended course of action and only a small proportion would not; request discussion if the intervention is not offered;*
- *for clinicians — most patients should receive the recommended course of action; and*
- *for policy makers — the recommendation can be adopted as a policy in most situations.*

## Evidence for communication recommendation

The communication recommendation made in this Guideline calls for communication assessment and intervention to be offered to children diagnosed with CBTL. This is required because communication difficulties are frequently reported in children diagnosed with CBTL (see Summary of Findings - Communication; Administrative & Technical Report, p. 37). Communication difficulties may be present for some children at the time of cancer diagnosis (e.g. Chieffo et al<sup>58</sup>; Mei & Morgan<sup>61</sup>) and/or during the cancer treatment phase (e.g. Brannon-Morris et al<sup>77</sup>; Taylor et al<sup>57</sup>). However, communication difficulties may also be seen in the longer-term, months or years after the completion of cancer treatment (e.g. Docking et al<sup>78</sup>; Levy et al<sup>79</sup>).

Communication difficulties have been shown across the areas of both speech and language (see Summary of Findings - Communication; Administrative & Technical Report, p. 37). Dysarthria or specific speech difficulties have been reported in this population such as prosodic problems,<sup>56,58,80-82</sup> poor articulation/speech intelligibility,<sup>56,58,62,81-83</sup> slow rate,<sup>56,62,80,83</sup> and voice problems.<sup>56,57,62,81-86</sup> Fluency difficulties have also been identified.<sup>58,85,87</sup> Mutism and/or dysarthria following surgery for cerebellar tumours surgery are well documented as part of post-operative cerebellar mutism syndrome

(pCMS).<sup>56,61,62,77,80-103</sup> For some children, mutism may resolve to dysarthria and/or language difficulties.<sup>61,80,83,86,90,95,99,101,102</sup> In the leukaemia population, specific speech difficulties have not been identified, but general difficulties in speech have been reported.<sup>57,79</sup>

For language, a range of difficulties have been identified including general oral language skills,<sup>38,56-59,78-80,85,90-92,94,101,102,104-108</sup> problems with word-finding,<sup>80,90,105</sup> narrative (story-telling) skills<sup>109</sup> and high-level language skills (such as inferencing, metaphors, jokes, and problem solving).<sup>38,60,78,106-108,110</sup> Literacy difficulties (pre-literacy skills, reading, writing, spelling) have also been reported.<sup>56,60,78,85,111-113</sup>

A strength of the literature evidence is that it unambiguously demonstrated the existence of communication difficulties in this population. However, there are a number of distinct limitations related to this body of evidence. First, there has been a reliance on descriptive study designs with small sample sizes. Second, heterogeneity across the literature in study design, participant factors, outcome measures and timing of assessment makes it impossible to determine the prevalence of communication difficulties in this population. Third, there is limited evidence related specifically to children with leukaemia.

In addition to literature evidence, the need for communication assessment and intervention in children diagnosed with CBTL was recognised in evidence systematically gathered from experts, health professionals and consumers. Communication skills were identified as foundational with significant impacts on quality-of-life and related outcomes such as academics, social connectedness and mental health. The potential for cascading effects into adulthood with implications for employment and participation in society was also highlighted.

This source of evidence also emphasised the need to consider diversity in the CBTL population when providing communication management. In the Health Professional and Consumer survey, consideration of risk factors was seen to be particularly important. Identified risk factors included child factors (e.g. age, socio-economic background, hospital stay), tumour properties (e.g. cancer location, brain tumour size) and cancer treatment (e.g. treatment type/combination, frequency) (see Administrative & Technical Report, Box C, p. 70). Given the inherent diversity in this population, communication assessment and intervention should be offered to all children diagnosed with CBTL in the context of an individualised approach to management.



*“Communication is a foundational skill which if problematic could have long lasting impacts on quality of life and functional outcomes such as the ability to complete school, enter university or obtain employment”  
(Steering Committee member)*

The desirable effects of providing communication assessment and intervention were rated by the Steering Committee (panel of experts) as large. The desirable effects focused on the improved communication outcomes that could be achieved if assessment and intervention was routinely offered to all children and the downstream benefits on quality-of-life, particularly for social and academic participation. The undesirable effects were rated as small. These related to feelings of stress, worry or frustration that could be experienced by the child or family in relation to testing and communication being *“just one more thing to worry about”*. Desirable effects were overwhelmingly rated as outweighing undesirable effects.



## Evidence for Key Practice Points

### Assessment & intervention

#### *When to assess*

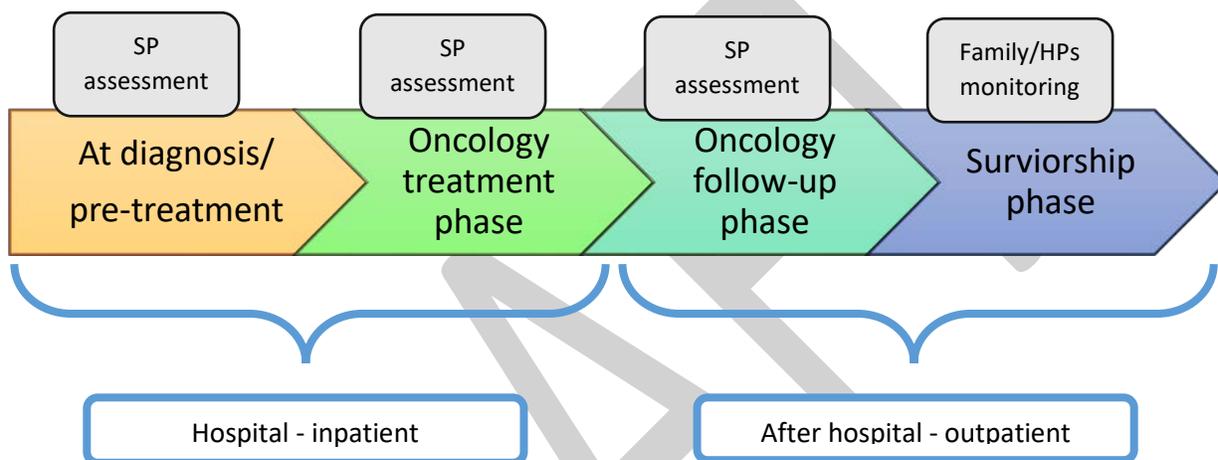
Assessment of communication needs to occur when a child is first diagnosed with brain tumour or leukaemia, during their cancer treatment and during oncology follow-up. Continued close monitoring by family and health professionals that have regular contact with the child should continue throughout during the survivorship years. This is because children diagnosed with CBTL may experience communication difficulties at one or more points in time across their oncology care and/or during the survivorship years (see Administrative & Technical Report, p. 21-22). Mutism and speech difficulties have mostly been studied and reported on in the shorter-term, while language difficulties have primarily been studied and reported on in the longer-term.



The importance of assessing regularly over time was also supported by the evidence collected from the experts, health professionals and consumers. In the Health Professional and Consumer survey, the need for regular communication assessment at crucial points across childhood was identified (see Administrative & Technical Report, p. 65). A clear message seen in both the survey of health professionals

and consumers and Steering Committee (panel of experts) comments was that communication outcomes would likely be improved and deleterious effects minimised if assessment and monitoring over time was routinely implemented. In Figure 5, the key practice points regarding assessment timing are embedded in the ‘timing and setting framework’, illustrating direct communication assessment across the first three phases and close monitoring and referral to Speech Pathology services if needed during the survivorship phase.

Figure 5. When to assess and when to monitor communication skills in CBTL

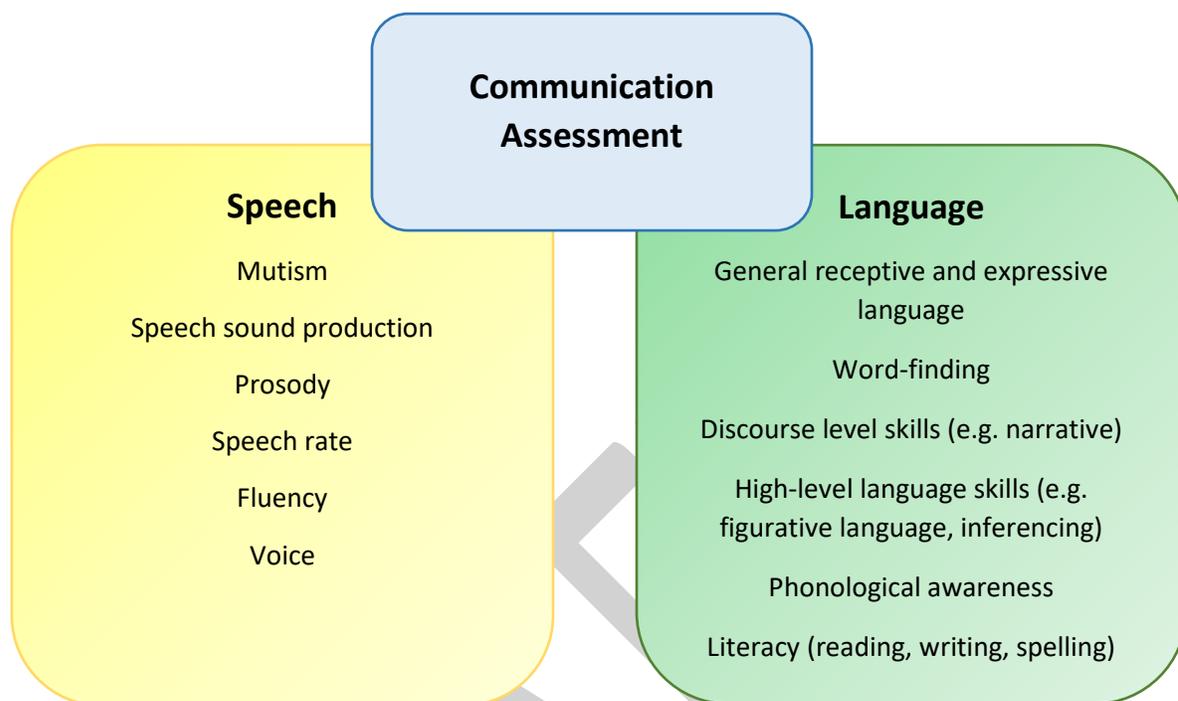


SP = Speech Pathology; HPs = Health professionals

#### *What to assess*

A broad range of communication difficulties may be experienced by children diagnosed with CBTL, across speech and language (see Summary of Findings - Communication; Administrative & Technical Report, p. 37). Therefore, it is crucial that comprehensive communication assessment is provided, taking into consideration the developmental level of the child, functional needs and family priorities. The literature evidence highlighted that a variety of assessment tools such as norm-referenced, criterion-referenced, care-giver report and observation across environments could be beneficial in understanding the nature of difficulties in this population (see Administrative & Technical Report, p. 21). The importance of comprehensive assessment was reflected in the health professional and consumer survey evidence where it was rated as very or extremely important by the majority of respondents (see Administrative & Technical Report, p. 65). Figure 6 outlines areas of communication that may need to be considered by the Speech Pathologist when planning a comprehensive communication assessment. This, of course, is dependent on the age of the child and priorities for the child/family.

Figure 6. Areas of communication to be considered for assessment in CBTL



#### *When to intervene*

Timely individualised intervention is crucial for children diagnosed with CBTL with identified communication difficulties. Given the broad range of speech and/or language difficulties that may be encountered across oncology phases (see Summary of Findings - Communication; Administrative & Technical Report, p. 37), intervention services need to be accessible across oncology care and into survivorship. Regular comprehensive communication assessment and monitoring across phases in the 'timing and setting framework' can ensure that timely intervention is provided to those children with identified difficulties.

The importance of intervention as required was supported by the health professional and consumer evidence (see Administrative & Technical Report, p. 65-66). In particular, early intervention, that is, intervention soon after cancer treatment, was raised as crucial in improving communication outcomes. Moreover,

*"Communication intervention is necessary, as needed, from the time of diagnosis, during treatment and beyond treatment"*  
(Health Professional and Consumer Group member)

ensuring availability of intervention services across oncology phases, including for those children who may have milder difficulties, was discussed.

### Care team

Communication difficulties are likely to be experienced by children with CBTL over time (see Administrative & Technical Report, p. 21-22) and therefore Speech Pathologists, as experts in communication development and disorders, are crucial members of the oncology care team both acutely and into the longer-term. The importance of the Speech Pathologist in the care team was reinforced by the health professional and consumer group evidence (see Administrative & Technical Report, p. 66-67). Overwhelmingly, Speech Pathologists were identified as the health professional most commonly involved in the management of communication difficulties, recognised for their direct role in assessment and intervention.



*“Speech pathologists are the experts in managing communication disorders...”  
(Health Professional & Consumer Group member)*

Multi-disciplinary care teams were highlighted by health professionals and consumers as essential for the successful management of communication in children diagnosed with CBTL (see Administrative & Technical Report, p. 66-67). A range of MDT members were identified as serving in the management of communication disorders. The most commonly identified team members included Speech Pathologists, Occupational Therapists, Education professionals, Neuropsychologists, Psychologists, Medical staff, Paediatricians, Nurses, Physiotherapists, Child Life Therapists, Oncologists, as well as families. The roles of each member were varied and included collaboration with the Speech Pathologist, implementing recommendations from the Speech Pathologist, consulting with the Speech Pathologist and family about related factors that may underlie or affect communication, facilitating and guiding overall rehabilitation as well as monitoring skills and advocating for the needs of the child.

### Education

Communication difficulties in children diagnosed with CBTL are complex. A wide range of difficulties may be experienced from trouble with producing clear speech, to difficulties with reading and writing (see Summary of Findings - Communication; Administrative & Technical Report, p. 37). The functional impacts of such difficulties may also present in varied ways such as finding it hard to make friends or

keep up with schoolwork. An additional complicating factor is that difficulties may be experienced across oncology phases (see Administrative & Technical Report, p. 21-22). Given this multi-layered complexity, education for families is crucial. This education needs to be provided early and continued over time. It needs to cover the common communication difficulties that may be experienced by children with CBTL and the potential for communication difficulties to continue or arise in the longer-term. This will provide families and teachers greater awareness and knowledge allowing them to identify communication needs that may arise, make referrals and advocate for the needs of the child, whether it be weeks after their cancer treatment or many years later. Evidence from the experts, health professionals and consumers also underscored the importance of education for families. The Steering Committee (panel of experts) identified that the value placed on communication by families may differ depending on the education/information they have received from health professionals. Families need to be informed about the importance of communication and the potential for communication difficulties as a consequence of CBTL. This will support them to make informed decisions and advocate for the needs of their child. In the survey, families as well as education professionals were identified as key members of the care team with particularly important roles related to day-to-day communication as well as monitoring and advocating (see Administrative & Technical Report, p. 67). However, in order to successfully take on these roles, it is essential that they receive appropriate education regarding communication development and disorders and their impact on academic and social skills.



*“Value placed on communication and swallowing will probably depend on people's own experiences ...have they been well informed by health professionals?”  
(Steering Committee member)*

### Implications for clinical practice

There are important considerations in planning for the adoption of this Guideline. In addition to guiding the process from research to recommendation, the GRADE EtD provided valuable context about the likely impact of this recommendation on clinical practice. As part of the GRADE EtD framework, the Steering Committee (panel of experts) considered five factors that weigh the risk versus benefit of recommendations. Specifically, these considerations included: resources required, cost effectiveness, equity, acceptability and feasibility. The implications on clinical practice described in Table 2 are based upon the detailed information provided in the GRADE EtD framework (see Administrative & Technical report, p.41-51).

Table 2. Implications of communication recommendation for clinical practice

<b>Implications for clinical practice</b>	<b>Summary of judgements and comments from GRADE EtD Framework</b>
Resources Required	<p><b>Costs and Savings</b></p> <p>The Steering Committee determined it is likely that there would be both costs and savings related to offering communication assessment/intervention to all children diagnosed with CBTL. Possible costs in the short-term may relate to the employment and upskilling of staff. However, there are potential long-term savings for the health sector, disability sector, education sector and families due to reduced impact of communication difficulties long-term.</p>
Cost Effectiveness	<p><b>Favours providing assessment/intervention</b></p> <p>The Steering Committee determined that communication assessment/intervention would be more cost effective compared to no communication assessment/intervention.</p> <p>The short-term costs of offering communication/intervention are likely to be small compared to long-term costs of treating more established disorders later in development. The cost benefits also extend to psychological, educational and employment outcomes.</p>
Equity	<p><b>Increased</b></p> <p>The Steering Committee determined that equity would be likely to be increased if communication assessment/intervention was offered to children diagnosed with CBTL. If the recommended minimum standard via a national Guideline was implemented, communication assessment/intervention would become routine. This would allow greater access to communication assessment/intervention, regardless of factors such as cultural and linguistic diversity, non-English speaking backgrounds, socio-economic status, geographical location and education levels.</p>
Acceptability	<p><b>Yes</b></p> <p>The Steering Committee determined that offering communication assessment/intervention would be acceptable to the majority of stakeholders, including families and health professionals.</p>
Feasibility	<p><b>Yes</b></p> <p>The Steering Committee determined that offering communication assessment/intervention would be feasible to incorporate into current services.</p>

	<p>There are few issues with regards to feasibility, except for funding and staffing resources.</p> <p>Note: Feasibility was considered by the Steering Committee prior to COVID-19. It is acknowledged that the financial impacts of this pandemic may last several years. However, it has since been considered that implementing this recommendation from a cost perspective within the current climate remains feasible.</p>
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# Swallowing Recommendation



Images/graphics in mock-up form only

## EVIDENCE-BASED RECOMMENDATION 2: SWALLOWING

Swallowing assessment and management should be offered to children diagnosed with childhood brain tumour or leukaemia	Strong Recommendation <sup>a</sup>
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### KEY PRACTICE POINTS

<b>Assessment &amp; Management</b>
<b><i>When to assess</i></b>
Swallowing assessment should occur at or as soon as possible after diagnosis of CBTL.
Swallowing assessment should occur during the oncology treatment phase. Multiple assessments may be required where concerns are indicated by the oncology care team and/or family.
Regular monitoring of the child's swallowing should continue throughout the oncology follow-up and survivorship phases until end of adolescence.
<b><i>What to assess</i></b>
A comprehensive swallowing assessment should be conducted. Assessment needs to be tailored to the age and developmental level of the child. All phases of the swallow (pre-oral anticipatory, oral-preparatory, oral and pharyngeal) need to be assessed.
Videofluoroscopy should be considered on a case-by-case basis as part of the assessment protocol to examine aspiration.
<b><i>When to intervene</i></b>
Children diagnosed with CBTL should be provided with early individualised management for swallowing difficulties during the oncology treatment phase.
Children diagnosed with CBTL should be provided with individualised management for swallowing difficulties identified by the oncology care team and/or family in the oncology follow-up and survivorship phases.
<b>Care Team</b>
Speech Pathologists should be involved as integral members of the oncology care team from the point of cancer diagnosis and throughout the oncology treatment phase to manage swallowing.
All members of the oncology care team should be informed about swallowing difficulties and involved in their management as needed throughout oncology phases.
Speech Pathologists should work in partnership with oncologists and family members to monitor swallowing throughout the survivorship phase until the end of adolescence.
<b>Education</b>
Education about swallowing difficulties in CBTL should be provided to families at cancer diagnosis or as early as possible.
Education about swallowing difficulties in CBTL should continue to be provided to families throughout the oncology treatment and follow-up phases.

<sup>a</sup> Based on GRADE EtD framework

## Strength of recommendation

The strength of this recommendation was determined through the use of the GRADE EtD Framework. The EtD framework provided a structured approach to determine the strength of recommendation, integrating the systematic review findings with pre-specified criteria. The Steering Committee provided input throughout the process. Further detailed information about the EtD process and the complete EtD framework for swallowing can be found in the accompanying Administrative and Technical Report (p. 38-40, p. 52-61).

Based on the results of the GRADE EtD Framework, this recommendation was rated as strong. This means that the Steering Committee was confident that the desirable effects of adherence to the recommendation outweighed the undesirable effects. The implications of a strong recommendation for patients, clinicians and policy makers as identified by GRADE<sup>76</sup> are:

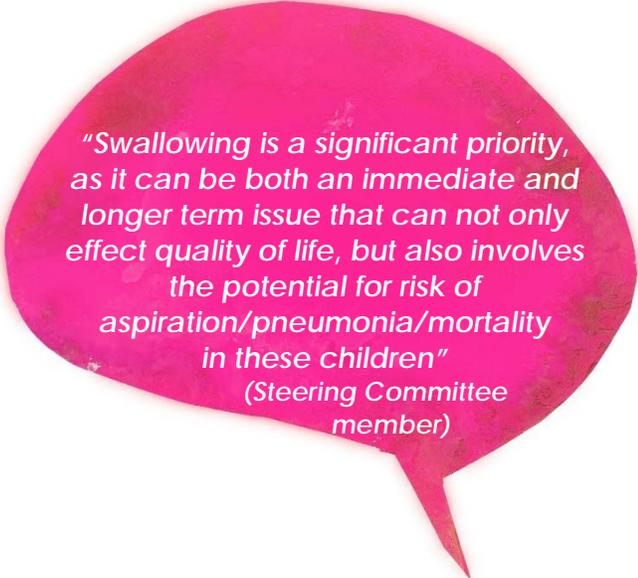
- *for patients — most people in your situation would want the recommended course of action and only a small proportion would not; request discussion if the intervention is not offered;*
- *for clinicians — most patients should receive the recommended course of action; and*
- *for policy makers — the recommendation can be adopted as a policy in most situations.*

## Evidence for swallowing recommendation

The swallowing recommendation made in this Guideline calls for swallowing assessment and management to be offered to children diagnosed with CBTL. This is vital because swallowing difficulties are frequently reported in children with CBTL (see Summary of Findings – Swallowing; Administrative & Technical Report, p. 37). Difficulties are most likely to be experienced during oncology treatment (e.g. Goncalves et al<sup>85</sup>; Newman et al<sup>70</sup>). For some children diagnosed with CBTL, particularly those children diagnosed with brain tumour, swallowing difficulties may continue into the longer-term (e.g. Brannon Morris et al<sup>77</sup>; Mei & Morgan<sup>61</sup>).

Acute swallowing difficulties in children with CBTL are typically characterised by difficulties across the oral preparatory and oral phase (e.g. reduced lip seal, food/liquid residue post-swallow, food spillage/drooling, impaired transfer of food in mouth) and the pharyngeal phase (e.g. initiation of swallow delayed, food/liquid residue in pharynx, coughing/gurgly voice, aspiration) of the swallow.<sup>57,61,69</sup> General clinical factors or pre-oral anticipatory factors that can impact swallowing ability such as fatigue and alertness/awareness may also be affected<sup>61,69</sup> and therefore need to be assessed. During the time when children are receiving cancer treatment, swallowing difficulties can be severe, with aspiration of food or liquids possible.<sup>70,114</sup> As a result, supplemental tube feeding may be required.<sup>57,61,69,73,77</sup>

It was clear from the literature evidence that swallowing difficulties exist in children with CBTL and are frequently seen immediately or soon after cancer treatment. However, there are limitations in the body of evidence that need to be considered. To date, studies have relied on descriptive designs and relatively small samples. Heterogeneity across studies in relation to participant factors, outcome measures and timing of assessments limit the ability to draw conclusions about the prevalence of swallowing difficulties in this population. Furthermore, there is a paucity of evidence related specifically to the swallowing outcomes of children with leukaemia.



*“Swallowing is a significant priority, as it can be both an immediate and longer term issue that can not only effect quality of life, but also involves the potential for risk of aspiration/pneumonia/mortality in these children”  
(Steering Committee member)*

The need for swallowing assessment and management for children diagnosed with CBTL was reflected in evidence systematically gathered from experts, health professionals and consumers. The possibility for swallowing difficulties to result in aspiration and to be life-threatening was emphasised. Ensuring adequate nutrition in the acute period was also highlighted. Longer-term swallowing difficulties and their potential to influence quality-of-life were also recognized such as the impact on independence, family mealtimes and social eating/fitting in with peers at school.

This source of evidence also emphasised the need to consider diversity in the CBTL population when providing swallowing management. In the Health Professional and Consumer survey, consideration of risk factors was seen to be particularly important. Identified risk factors included child factors (e.g. age, socio-economic background, hospital stay), swallowing-related factors (e.g. prolonged tube feeding, poor physical positioning), tumour properties (e.g. cancer location, brain tumour size) and cancer treatment (e.g. treatment type/combination, frequency) (see Administrative & Technical Report, Box C, p. 70). Given the inherent diversity in this population, swallowing assessment and management should be offered to all children diagnosed with CBTL in the context of an individualised approach.

The desirable effects of providing swallowing assessment and management were rated by the Steering Committee (panel of experts) as large. The desirable effects focused on the safe swallowing of fluids and food and the prevention of aspiration and subsequent health complications such as chest infections and pneumonia. The undesirable effects were rated as small and related to the potential for stress/anxiety related to assessment for children and family. The desirable effects were rated as outweighing the undesirable effects.



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

## Evidence for Key Practice Points

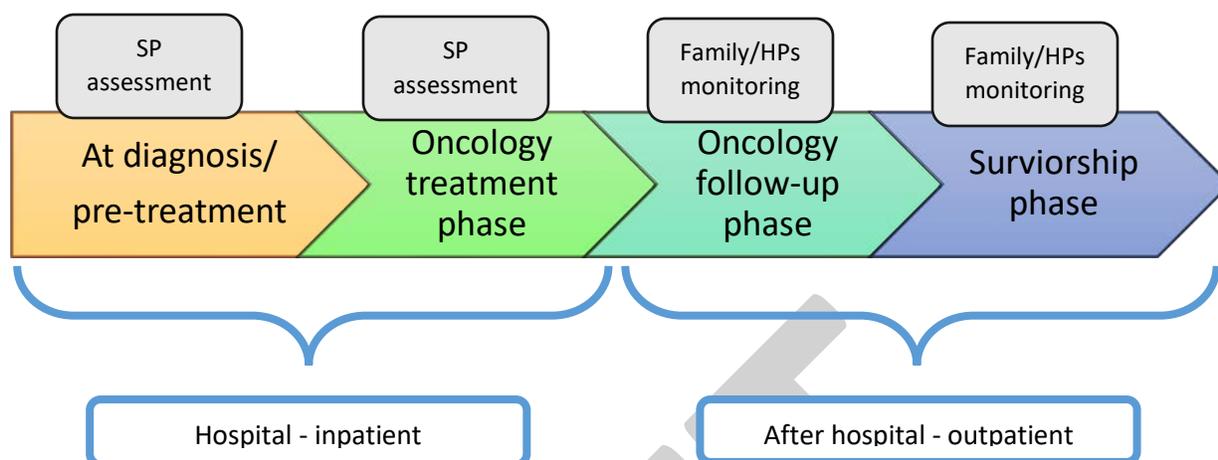
### Assessment & intervention

#### *When to assess*

Swallowing assessment is vital at cancer diagnosis and during the oncology treatment phase. Research has identified that swallowing difficulties are frequent during these phases.<sup>57,61,69,70,73,77,85,114-117</sup> During oncology follow-up and survivorship, continued close monitoring of swallowing by family and involving health professionals with referral as needed is warranted given some evidence of longer-term swallowing impacts.<sup>61,69,73,77,115</sup>

The evidence from experts, health professionals and consumers also supported the need for swallowing assessment to occur in the acute phases. One member of the Steering Committee (panel of experts) reported that the assessment of swallowing should be as commonplace as measuring temperature during the post-operative period. The importance of safe swallowing and the need to minimise the risk of aspiration and subsequent chest infections/pneumonia during oncology treatment were key themes in the committee’s discussion. Regular swallowing assessment and/or monitoring was viewed as necessary by the majority of health professionals and consumers in the survey results and was thought to contribute to improved swallowing outcomes (see Administrative & Technical Report, p. 66). In Figure 7, key practice points regarding timing of swallowing assessment are embedded in the ‘timing and setting framework’.

Figure 7. When to assess and when to monitor swallowing skills in CBTL



SP = Speech Pathology; HPs = Health professionals

#### What to assess

Given that swallowing difficulties may be across multiple phases of swallowing<sup>57,61,69</sup>, comprehensive assessment that examines pre-oral anticipatory factors such as alertness and awareness, oral-preparatory, oral and pharyngeal phases of the swallow is needed. The systematic review of the evidence revealed most swallowing assessments were conducted via clinical observation with or without a specific checklist (see Administrative & Technical Report, p. 21). Five studies included videofluoroscopy in assessment of children with CBTL to identify aspiration<sup>61,70,73,114,115</sup> indicating that it may be a useful tool to consider as part of assessment for this population. The rationale for performing videofluoroscopy was not definitive in the literature. Thus, Speech Pathologists should be guided by the findings from bedside assessment and their clinical judgement and expertise to make decisions about the need for videofluoroscopy on a case-by-case basis. The provision of comprehensive swallowing assessment for children diagnosed with CBTL was seen as important by the majority of the health professionals and consumers and related to improved swallowing outcomes for this population (see Administrative & Technical Report, p. 66).

### *When to intervene*

Given that children with CBTL are likely to show evidence of swallowing difficulties at diagnosis and/or during oncology treatment (see Summary of Findings – Swallowing; Administrative & Technical Report, p. 37), immediate management is needed at these early oncology phases for those with identified difficulties following assessment. This was reflected in comments from the experts, health professionals and consumers who overwhelmingly recognized the need for swallowing management during the acute phases of diagnosis and cancer treatment. They identified that appropriate management would result in improved swallowing outcomes and reduce longer-term adverse effects related to medical health and quality-of-life.

In the oncology follow-up and survivorship phases, some children diagnosed with CBTL may require direct swallowing management as research evidence shows persistent difficulties can be possible, although limited in the length of follow-up.<sup>61,69,73,77,115</sup> In such cases, monitoring and identification of swallowing difficulties by the oncology care team and/or family is crucial. It is important that those responsible for monitoring can refer to Speech Pathology services for swallowing assessment and decisions regarding management can subsequently be made on a case-by-case basis.

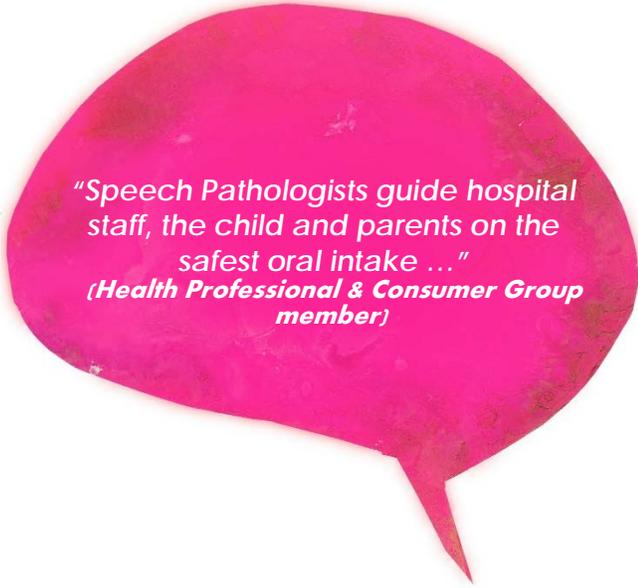
### *Care team*

Speech Pathologists have expertise in the assessment and management of swallowing and therefore should be integral to the oncology care team. Health professional and consumer survey evidence supported this, with Speech Pathologists the most frequently identified member required as part of the team in the management of swallowing (see Administrative & Technical Report, p. 68).

The importance of multi-disciplinary care teams in joint management of swallowing was also identified by the Health Professional and Consumer Group (see Administrative &



*“Imperative that swallowing is assessed and treated without delay, due to the significant consequences if left untreated”  
(Steering Committee member)*



*“Speech Pathologists guide hospital staff, the child and parents on the safest oral intake ...”  
(Health Professional & Consumer Group member)*

Technical Report, p. 66, 68). In particular, they acknowledged the essential roles of dieticians and doctors in assessing nutritional status/needs and recommending/providing supplemental feeding options. The role of doctors, nurses, oncologists, psychologists, pediatricians as well as family in the monitoring of overall clinical state and day-to-day swallowing functioning was highlighted.

## Education

Considering the potentially life-threatening consequences of swallowing difficulties and possible long-term quality-of-life impacts, it is crucial that families of children with CBTL receive appropriate education about the nature and course of such difficulties. Education about aspiration and its medical consequences, safe swallowing practices, food/fluid consistencies, supplemental feeding and the importance of monitoring swallowing into the long-term is needed. As swallowing difficulties are most likely evident during the acute oncology phases (see Administrative & Technical Report, p. 21-22), education needs to be provided at or soon after cancer diagnosis, with continued education throughout oncology treatment. Upon hospital discharge, education about the potential for long-term swallowing difficulties and management and the role of the family in monitoring and referral is needed. One member of the Steering Committee (panel of experts) recognised that the value placed on swallowing assessment and management may be influenced by how well-informed they have been, thus, emphasising the key role of education about swallowing in this population.



*"The value placed on swallowing assessment and management depends, among others, on how well informed they have been..."*  
(Steering Committee member)

## Implications for clinical practice

There are important considerations in planning for the adoption of this Guideline. In addition to guiding the process from research to recommendation, the GRADE EtD provided valuable context about the likely impact of this recommendation on clinical practice. As part of the GRADE EtD framework, the Steering Committee (panel of experts) considered five factors that weigh the risk versus benefit of recommendations. Specifically, these considerations included: resources required, cost effectiveness, equity, acceptability and feasibility. The implications on clinical practice described in Table 3 are based upon the detailed information provided in the GRADE EtD framework (see Administrative and Technical report, p.52-61).

Table 3. Implications of swallowing recommendation for clinical practice

Implications for clinical practice	Summary of judgements and comments from GRADE EtD Framework
Resources Required	<p><b>Negligible costs</b></p> <p>The Steering Committee determined that there were negligible costs related to offering swallowing assessment/management to children diagnosed with CBTL. They recognised that the resources to provide assessment and management in the acute phases were already available, however, longer-term follow-up could require additional resources in relation to staff, education and assessment tools. Health professionals time was the main resource identified.</p>
Cost Effectiveness	<p><b>Favors providing assessment/management</b></p> <p>The Steering Committee determined that swallowing assessment/management would be more cost effective compared to no swallowing assessment/management. Providing management was seen as outweighing the potential negative impacts of swallowing difficulties related to aspiration, chest infection and hospital stay length.</p>
Equity	<p><b>Increased</b></p> <p>The Steering Committee determined that equity would be likely to be increased if swallowing assessment/management was offered to children diagnosed with CBTL. In particular, equity may be increased for children from non-English speaking backgrounds or lower socio-economic backgrounds where families may be less able to identify swallowing difficulties or advocate for needs. One member of the Steering Committee noted that more targeted approaches to identifying which children need swallowing assessment/management would be preferable to the current “status-quo”.</p>
Acceptability	<p><b>Yes</b></p> <p>The Steering Committee determined that offering swallowing assessment/management would be acceptable to the majority of stakeholders, including families and health professionals.</p>
Feasibility	<p><b>Yes</b></p> <p>The Steering Committee determined that offering swallowing assessment/management would be feasible to incorporate into current services. However, they did recognise that this would depend on funding and staffing</p>

	<p>resources. It was recognised that it is not onerous and mostly requires time from the Speech Pathologist.</p> <p>Note: Feasibility was considered by the Steering Committee prior to COVID-19. It is acknowledged that the financial impacts of this pandemic may last several years. However, it has since been considered that implementing this recommendation from a cost perspective within the current climate remains feasible.</p>
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# Clinical Practice Guideline for the Management of Communication and Swallowing in Children Diagnosed with Childhood Brain Tumour or Leukaemia



images/graphics in mock-up form only

**Administrative & Technical Report**  
Draft for Public Consultation – July 13, 2020

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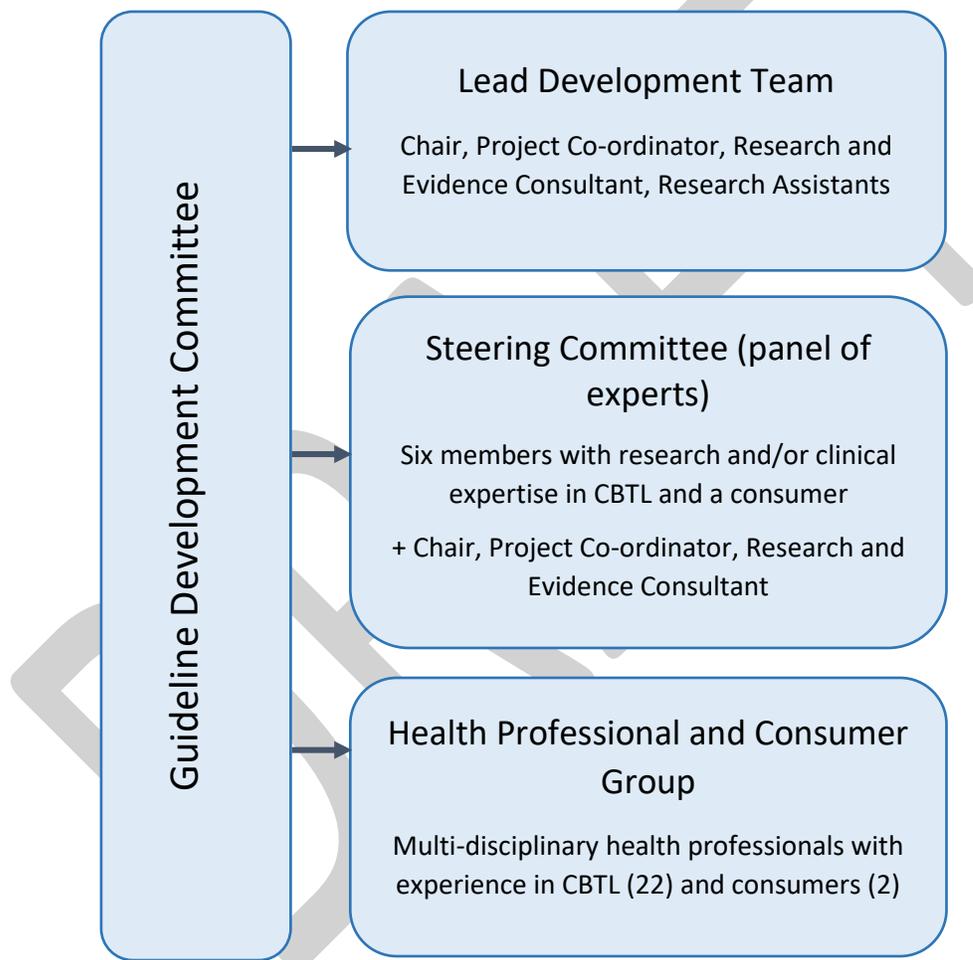
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# Guideline Development Committee

## 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.

Figure 1. Guideline Development Committee



CBTL = Childhood brain tumour or leukaemia

## 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 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 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 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.

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Table 1. 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-coordinator	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 Assistant	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)
Professor Philippe Paquier <i>Vrije Universiteit Brussel (VUB) &amp; Université Libre de Bruxelles (ULB)</i>	Steering Committee	None to declare
Dr Luciano Dalla-Pozza <i>Cancer Centre for Children, The Children's Hospital at Westmead</i>	Steering Committee	None to declare
Dr Mary-Clare Waugh <i>The Children's Hospital at Westmead, The University of Sydney Medical School</i>	Steering Committee	None to declare
Ms Maria Messina <i>Consumer</i>	Steering Committee	None to declare
Ms Claire Radford <i>Queensland Children's Hospital</i>	Health Professional and Consumer Group	None to declare
Ms Brooke Spencer <i>Queensland Children's Hospital</i>	Health Professional and Consumer Group	None to declare
Ms Hayley Coulson <i>Queensland Children's Hospital</i>	Health Professional and Consumer Group	None to declare

Dr Cinzia De Luca <i>The Royal Children's Hospital, Melbourne</i>	Health Professional and Consumer Group	None to declare
Ms Candice Brady <i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network</i>	Health Professional and Consumer Group	None to declare
Ms Suzi Drevensek <i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network</i>	Health Professional and Consumer Group	None to declare
Dr Robyn Stargatt <i>La Trobe University</i>	Health Professional and Consumer Group	None to declare
Ms Amanda Simon <i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network</i>	Health Professional and Consumer Group	None to declare
Ms Kate Osland <i>The Children's Hospital at Westmead. Sydney Children's Hospitals Network</i>	Health Professional and Consumer Group	None to declare
Ms Gloria Tzannes <i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network</i>	Health Professional and Consumer Group	None to declare
Ms Melissa Parkin <i>Sydney Children's Hospital Randwick, Sydney Children's Hospitals Network</i>	Health Professional and Consumer Group	None to declare
Dr Jennifer Cohen <i>Discipline of Paediatrics, School of Women's and Children's Health, University of NSW</i>	Health Professional and Consumer Group	None to declare
Dr Laura Janzen <i>The Hospital for Sick Children, Toronto</i>	Health Professional and Consumer Group	None to declare
Ms Jane Fong <i>Women's and Children's Hospital, Adelaide</i>	Health Professional and Consumer Group	None to declare
Ms Lauren Leeming <i>Sydney Children's Hospital Network</i>	Health Professional and Consumer Group	None to declare
Dr Amanda Lane-Brown <i>Sydney Children's Hospital Network</i>	Health Professional and Consumer Group	None to declare
Ms Roxanne McLeod <i>Sydney Children's Hospital Network</i>	Health Professional and Consumer Group	None to declare
Miriam Cromie <i>Child Life and Music Therapy, The Children's Hospital at Westmead</i>	Health Professional and Consumer Group	None to declare

Geoff McCowage <i>The Children's Hospital at Westmead</i>	Health Professional and Consumer Group	None to declare
Eliza-Jane Potter <i>The Children's Hospital at Westmead</i>	Health Professional and Consumer Group	None to declare
Dr Sumanth Nagabushan <i>The Children's Hospital at Westmead, Sydney Children's Hospitals Network; The University of Sydney</i>	Health Professional and Consumer Group	None to declare
Jessica De Bolfo <i>The Royal Children's Hospital Melbourne</i>	Health Professional and Consumer Group	None to declare
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

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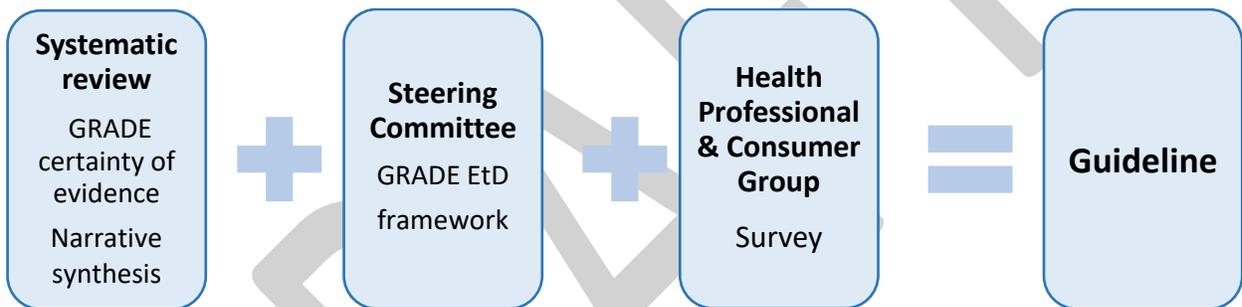
# Guideline Development Process

## Guideline development: evidence sources

The two main recommendations in this Guideline 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 Evidence-to-Decision (EtD) framework
- 3) Input of a Health Professional and Consumer Group via a survey

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

## Public consultation

During June 2020, direct invitations to view and provide comment on the draft Guideline were sent to relevant professional and consumer organisations (see Appendix A for list of invited organisations). The Guideline was released for public consultation on The University of Sydney website on July 13, 2020. The public consultation summary and team's responses to this can be viewed here: [to be updated post public consultation].

## Independent expert and methods review

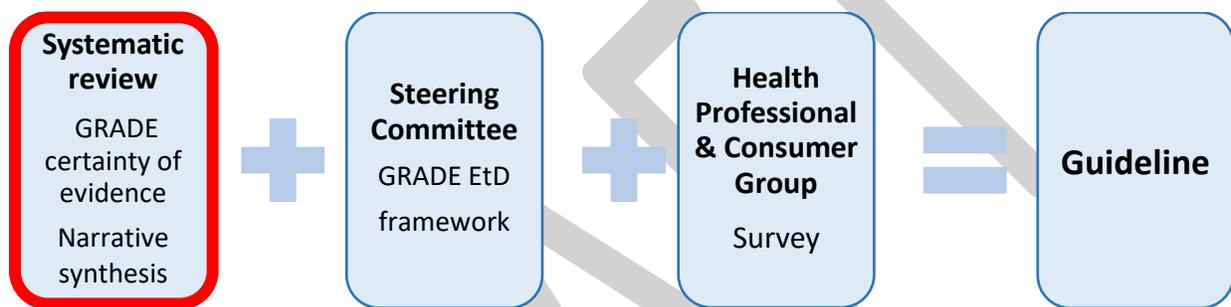
Anonymous, independent review of the Guideline using the Agree II instrument<sup>1</sup> was facilitated by NHMRC and completed following public consultation in [insert month] 2020. Independent reviewers were selected from a list of six potential reviewers nominated by the Chair. Their reviews can be viewed here: [to be updated post independent review]. Methods review was commissioned by NHMRC and can be viewed here: [to be updated post independent review].

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# 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] guidelines<sup>2</sup> 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 al, in preparation<sup>3</sup>). The methods and results of the systematic review are detailed below.

Figure 3. One source of evidence to inform guidelines: Systematic review



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

## 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.<sup>4</sup> The PICOTS typology is suited to review questions that seek to examine the most likely course/outcome for individuals with a certain health condition.<sup>4</sup> The clinical questions are shown in the box below:

## Box A. Clinical questions

Communication Outcomes	<i>What are the communication outcomes associated with childhood brain tumour or leukaemia?</i>
Swallowing Outcomes	<i>What are the swallowing outcomes associated with childhood brain tumour or leukaemia?</i>

### 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.<sup>4,5</sup>

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 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 will be 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<sup>a</sup> and available in the English language.<sup>b</sup>

#### *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  $\leq 16$  years old).

#### *Types of prognostic factors*

Any type of childhood brain tumour or leukaemia.

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<sup>a</sup> In initial search strategy, a wider date range (1988 – 2019) was used. However, at the full-text assessment, this was refined to 1998 – 2019

<sup>b</sup> In initial search strategy, English language was not selected as a filter. However, this was applied at the full-text assessment stage

### *Types of outcome measures*

Speech, language<sup>c</sup> 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.

### *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.

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<sup>c</sup>To be included, studies needed to use sufficiently detailed assessment of language skills, beyond one subtest of a larger cognitive or neuropsychological battery.

### *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](https://joannabriggs.org/ebp/critical_appraisal_tools)).<sup>6,7</sup> 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.<sup>8</sup> 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.<sup>9</sup> 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

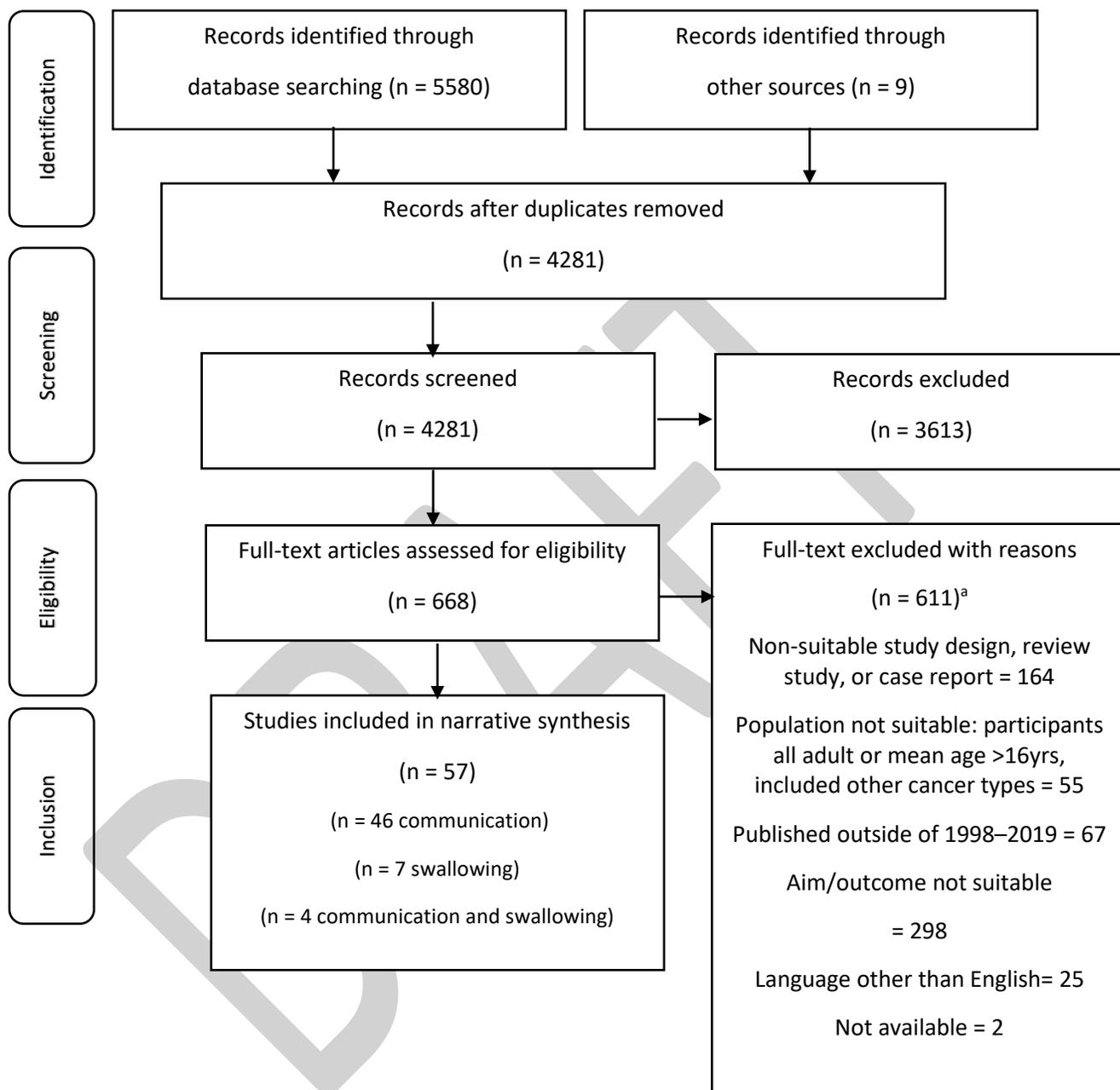
Adapted from Hodges et al, in preparation<sup>3</sup>

## 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 al, in preparation<sup>3</sup>)



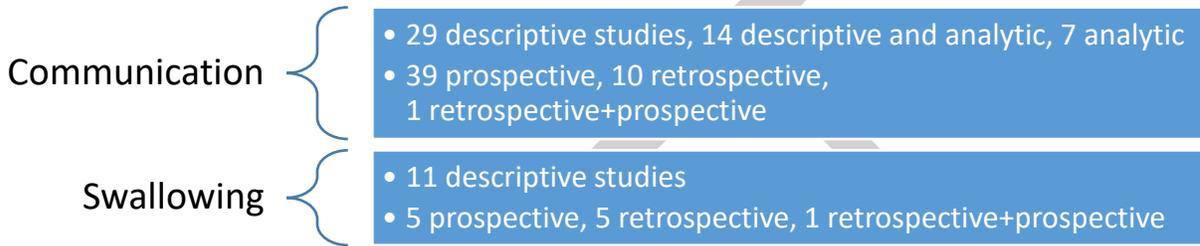
<sup>a</sup>Three additional exclusion criteria were applied at full-text assessment: case reports, studies published in a language other than English and studies published prior to 1998.

## 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.

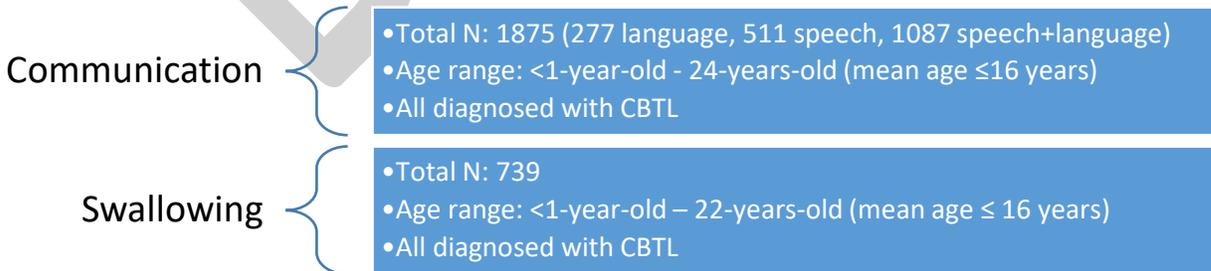
Figure 5. Study designs for included studies by outcome



### 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 was 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 a mixed adult/child sample were included if the mean age of the participants was  $\leq 16$  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.

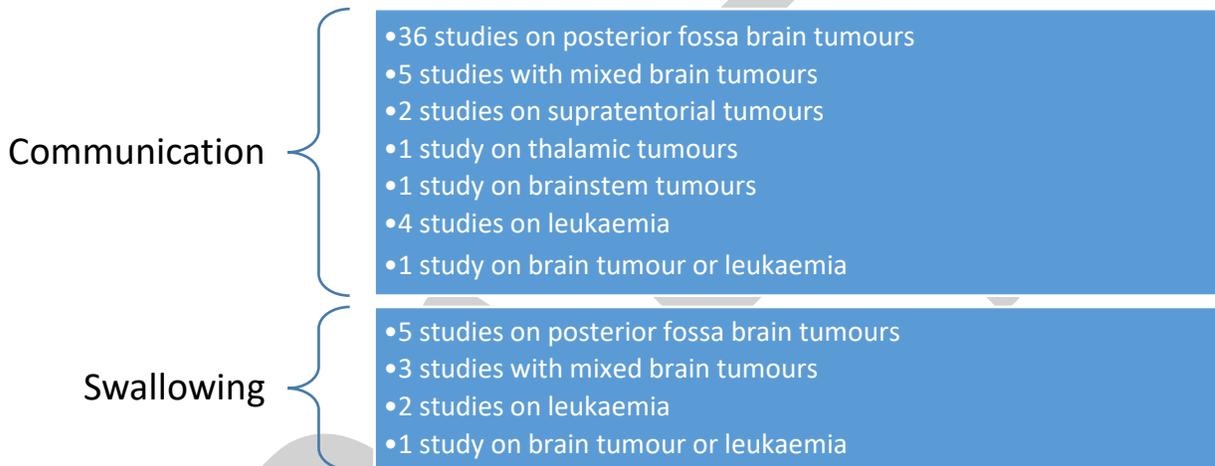
Figure 6. Number and types of participants in included studies by outcome



### 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.

Figure 7. Prognostic factors (cancer diagnoses) of participants in included studies by outcome



### 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 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

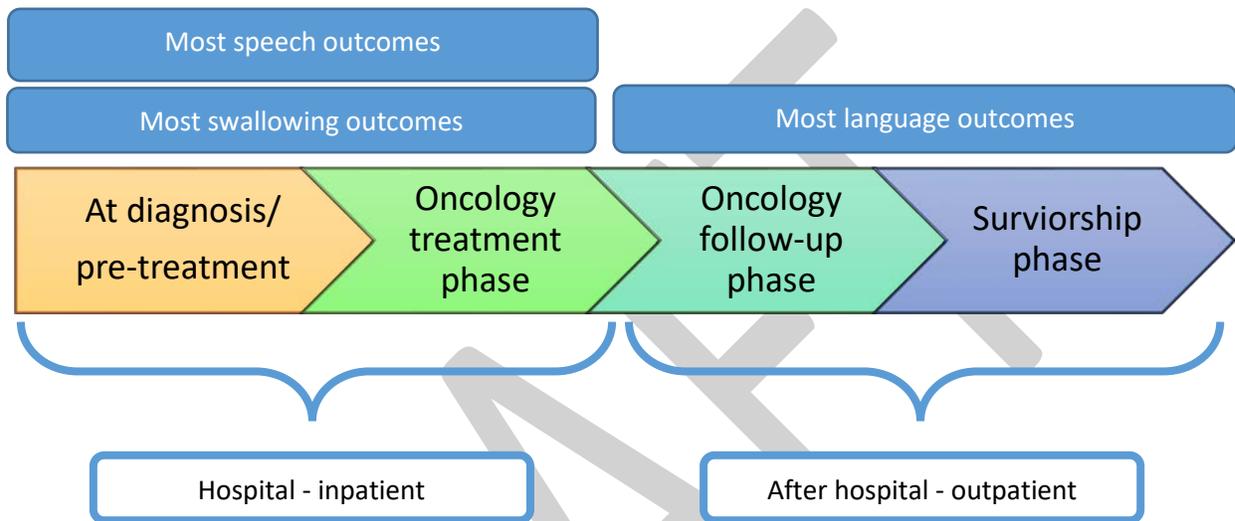


Table 2. Characteristics of included studies: Communication (speech, language, speech+language) (Hodges et al, in preparation<sup>3</sup>)

Study	Study design	No of participants	Age (range) & cancer type	Outcome measure	Timing	Setting
<b>SPEECH</b>						
Beckwitt et al, 2012 <sup>10</sup>	Descriptive Prospective	22	14 months - 17 yrs BT: posterior fossa	Presence of PFS	Dx/PT OTP	Inpatient
Brannon Morris et al, 2009 <sup>11</sup>	Descriptive Prospective	42	8 months - 22.7 yrs BT: posterior fossa	Observational rating scale	OTP OFuP SP	Inpatient Outpatient
Catsman-Berrevoets et al, 1999 <sup>12</sup>	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
Cornwell et al, 2005 <sup>13</sup>	Descriptive Prospective	6 (+6 comparison)	6.5 - 13.3 yrs BT: posterior fossa	Standardised assessment, perceptual and physiological analyses of speech sample	OFuP	Outpatient
Cornwell et al, 2003 <sup>14</sup>	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
Cornwell et al, 2004 <sup>14</sup>	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
De Smet et al, 2012 <sup>15</sup>	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

Huber et al, 2007 <sup>16</sup>	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
Korah et al, 2010 <sup>17</sup>	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
Kotil et al, 2008 <sup>18</sup>	Descriptive Prospective	32	3 - 13 yrs BT: posterior fossa	Presence of CM using a checklist	Dx/PT OTP OFuP	Inpatient Outpatient
Kupeli et al, 2011 <sup>19</sup>	Descriptive Prospective	36	Range not reported, all <16 yrs BT: posterior fossa	Presence of PFS	Dx/PT OTP	Inpatient
Liu et al, 2018 <sup>20</sup>	Descriptive Retrospective	89	2 - 23 yrs BT: posterior fossa	Reduced/absent speech ascertained from chart using pro-forma	OTP	Inpatient
Mei & Morgan, 2011 <sup>21</sup>	Descriptive Retrospective	27	2 - 18 yrs BT: posterior fossa	Presence of mutism and dysarthria ascertained from chart	Dx/PT OTP OFuP	Inpatient Outpatient
Morgan et al, 2011 <sup>22</sup>	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
Ozimek et al, 2004 <sup>23</sup>	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/PT OTP	Inpatient

Richter, Schoch, Ozimek et al, 2005 <sup>24</sup>	Analytic Prospective	10 (+ 10 controls)	8 - 16 years BT: posterior fossa	Perceptual and acoustic speech analyses, diadochokinetic rate, sentence production	Dx/PT OTP	Inpatient
Van Mourik et al, 1998 <sup>25</sup>	Descriptive Prospective	12	4 - 14 yrs BT: posterior fossa and brainstem	Perceptual speech analysis	Dx/PT OTP	Inpatient
Wells et al, 2010 <sup>26</sup>	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
<b>LANGUAGE</b>						
Ait Khelifa-Gallois et al, 2015 <sup>27</sup>	Analytic Prospective	17 (+ 61 controls)	6.7 -17.9 yrs BT: posterior fossa	Standardised reading assessments, clinical observation	SP	Outpatient
Docking et al, 2016 <sup>28</sup>	Descriptive-analytic Prospective	17 (+17 controls)	5.6 - 14.11 yrs BT: mixed	Criterion-referenced narrative assessment, analysis of macrostructure and microstructure	OFuP SP	Outpatient
Docking et al, 2003a <sup>29</sup>	Descriptive-analytic Prospective	6 (+6 controls)	3.10 - 14.1 yrs BT: supratentorial	Standardised language assessments	OFuP SP	Outpatient
Docking et al, 2003b <sup>30</sup>	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
Docking et al, 2004 <sup>31</sup>	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

Docking et al, 2005 <sup>32</sup>	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
Dowling et al, 2014 <sup>33</sup>	Descriptive-analytic Prospective	7 (+7 controls)	6.2 - 8.2 yrs Leukaemia: ALL	Standardised high-level language assessment: figurative language subtest	OFuP SP	Outpatient
Kirschen et al, 2008 <sup>34</sup>	Analytic Prospective	12 (+12 controls)	6 - 19 yrs BT: posterior fossa	Standardised phonological processing and phonemic/verbal fluency assessments	OFuP SP	Outpatient
Lafay-Cousin et al, 2009 <sup>35</sup>	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
Levisohn et al, 2000 <sup>36</sup>	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
Lewis & Bohan, 2018 <sup>37</sup>	Descriptive Prospective	5	10.2 - 15.1 yrs Leukaemia: ALL	Standardised language assessments, including high-level language	SP	Outpatient
Lewis & Murdoch, 2011 <sup>38</sup>	Descriptive-analytic Prospective	4 (+20 control)	5.1 - 14.1 yrs BT: posterior fossa	Standardised language assessments, including high-level language	SP	Outpatient
Lewis & Murdoch, 2013 <sup>39</sup>	Descriptive Prospective	4	5.1 - 16.1 yrs BT: posterior fossa	Standardised language assessments, including high-level language	OFuP SP	Inpatient Outpatient
Lewis et al, 2011 <sup>40</sup>	Analytic Prospective	13 (+13 controls)	4.8 - 14.8 yrs Leukaemia: ALL	Standardised language assessments, including high-level language	OFuP SP	Outpatient

Lonnerblad et al, 2017 <sup>41</sup>	Descriptive Retrospective	45	9 - 18 yrs BT: mixed	Standardised literacy assessment	OFuP SP	Outpatient
Murdoch et al, 2004 <sup>42</sup>	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
Palmer et al, 2014 <sup>43</sup>	Descriptive- analytic Prospective	81	4 - 21 yrs BT: posterior fossa	Standardised assessment of reading decoding	OTP	Inpatient
<b>SPEECH + LANGUAGE</b>						
Aarson et al, 2004 <sup>44</sup>	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
Catsman- Berrevoets & Aarsen, 2010 <sup>45</sup>	Descriptive Prospective	148 with BT examined; 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
Chieffo et al, 2014 <sup>46</sup>	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

De Smet et al, 2009 <sup>47</sup>	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
Di Rocco et al, 2011 <sup>48</sup>	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
Di Rocco et al, 2010 <sup>49</sup>	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
Frank et al, 2007 <sup>50</sup>	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
Frank et al, 2008 <sup>51</sup>	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

Goncalves et al, 2008 <sup>52</sup>	Descriptive Prospective	190	1 - 20 yrs BT: Mixed	A screening process: clinical protocol and a questionnaire	OTP	Inpatient
Grieco et al, 2019 <sup>53</sup>	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
Levy et al, 2013 <sup>54</sup>	Descriptive Retrospective	13	2.9 - 13.9 yrs Leukaemia: mixed	Neurocognitive testing which showed speech/language difficulties	OFuP SP	Outpatient
Richter, Schoch, Kaiser et al, 2005 <sup>55</sup>	Analytic Prospective	12 (+27 controls)	9 - 19 yrs BT: posterior fossa	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	OFuP SP	Outpatient
Riva & Giorgi, 2000 <sup>56</sup>	Descriptive Retrospective	26	6.0 - 13.4 yrs BT: posterior fossa	Language: Standardised language assessments, mean length of utterance, observations in spontaneous sample Speech: observations in spontaneous sample	OTP OFuP	Inpatient Outpatient
Robertson et al, 2006 <sup>57</sup>	Analytic Prospective	450	Range not reported. Median age at dx with CMS 7.3 yrs; those without CMS 8.0 yrs BT: posterior fossa	CM survey, general assessment of neurological and developmental outcomes (including speech and language) at 1 year post surgery	OTP OFuP	Inpatient Outpatient

Taylor et al, 2012 <sup>58</sup>	Descriptive Retrospective	47	Range not reported. All ≤16 yrs Leukaemia and BT	Presence/absence of communication difficulties	OTP OFuP	Inpatient Outpatient
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**Abbreviations:** BT, brain tumour; ALL, Acute Lymphoblastic Leukaemia; PFS, Posterior Fossa Syndrome; CM, Cerebellar Mutism; CMS, Cerebellar Mutism Syndrome; Dx/PT, at diagnosis/pre-treatment; OTP, oncology treatment phase; OFuP, oncology follow-up phase; SP, survivorship phase

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Table 3. Characteristics of included studies: Swallowing (Hodges et al, in preparation)

Citation	Study design	No of participants	Age (range) & cancer type	Outcome measure	Timing	Setting
Brannon Morris et al, 2009 <sup>11</sup>	Descriptive Prospective	42	8 months - 22.7 yrs BT: posterior fossa	Observational rating scale	OTP OFuP SP	Inpatient Outpatient
Fayoux et al, 2011 <sup>59</sup>	Descriptive Retrospective	5	0.11 - 4.4 yrs BT: brainstem tumour, vagal ganglioneuroma	Observational, videofluoroscopy	Dx/PT OTP OFuP	Inpatient Outpatient
Goncalves et al, 2008 <sup>52</sup>	Descriptive Prospective	190	1 - 20 yrs BT: mixed	Patient-reported swallowing problem, direct screening of presence/absence of swallowing difficulties	OTP	Inpatient
Hanna et al, 2016 <sup>60</sup>	Descriptive Prospective	46	2 - 12 yrs Leukaemia: ALL	Clinical examination by dentist. Dysphagia considered among other dental/oral problems	Dx/PT OTP	Inpatient
Lee et al, 2016 <sup>61</sup>	Descriptive Retrospective & 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
Mei & Morgan, 2011 <sup>21</sup>	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

Morgan et al, 2008 <sup>62</sup>	Descriptive Prospective	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
Nagy et al, 2019 <sup>63</sup>	Descriptive Retrospective	19	0.11 - 17 yrs BT: mixed	Clinical observation plus videofluoroscopy in some cases	OTP	Inpatient
Newman et al, 2006 <sup>64</sup>	Descriptive Retrospective	127 cases reviewed; 24 included for further examination	0.8 - 17.9 yrs BT: posterior fossa	Videofluoroscopy	OTP	Inpatient
Ribeiro et al, 2017 <sup>65</sup>	Descriptive Prospective	42	2 - 18 yrs Leukaemia: ALL	A criterion-referenced oral assessment tool included section on swallowing	OTP	Inpatient
Taylor et al, 2012 <sup>58</sup>	Descriptive Retrospective	47	Range not reported. All ≤16 yrs Leukaemia and BT	Presence/absence of swallowing difficulty	OTP OFuP	Inpatient Outpatient

**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).

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Table 4. Individual quality assessment and GRADE certainty of evidence: Speech

Citation	JBI appraisal score	Certainty of evidence (GRADE)					
		Risk of bias	Inconsistency	Publication bias	Imprecision	Indirectness	Overall certainty
Beckwitt et al, 2012	9/10	serious concerns	no concerns	not detected	very serious concerns	no concerns	very low
Brannon Morris et al, 2009	10/10						
Catsman-Berrevoets et al, 1999	7/10						
Cornwell et al, 2005	7/10						
Cornwell et al, 2003	5/11						
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	JBI appraisal score	Certainty of evidence (GRADE)					
		Risk of bias	Inconsistency	Publication bias	Imprecision	Indirectness	Overall certainty
Ait Khelifa-Gallois et al, 2015	5/11	serious concerns	no concerns	not detected	very serious concerns	no concerns	very low
Docking et al, 2016	6/11						
Docking et al, 2003a	5/11						
Docking et al, 2003b	5/11						
Docking et al, 2004	4/11						
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	Inconsistency	Publication bias	Imprecision	Indirectness	Overall certainty
Aarson et al, 2004	9/10	serious concerns	no concerns	not detected	serious concerns	no concerns	very low
Catsman-Berrevoets & Aarson, 2010	10/10						
Chieffo et al, 2014	10/10						
De Smet et al, 2009	7/10						
Di Rocco et al, 2011	10/10						
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	JBİ appraisal score
Brannon Morris et al, 2009	10/10
Fayoux et al, 2011	8/10
Goncalves et al, 2008	9/10
Hanna et al, 2016	7/10
Lee et al, 2016	10/10
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

Certainty of evidence (GRADE)					
Risk of bias	Inconsistency	Publication bias	Imprecision	Indirectness	Overall certainty
serious concerns	no concerns	not detected	very serious concerns	no concerns	<b>very low</b>

Table 8. GRADE summary of findings per outcome (narrative)

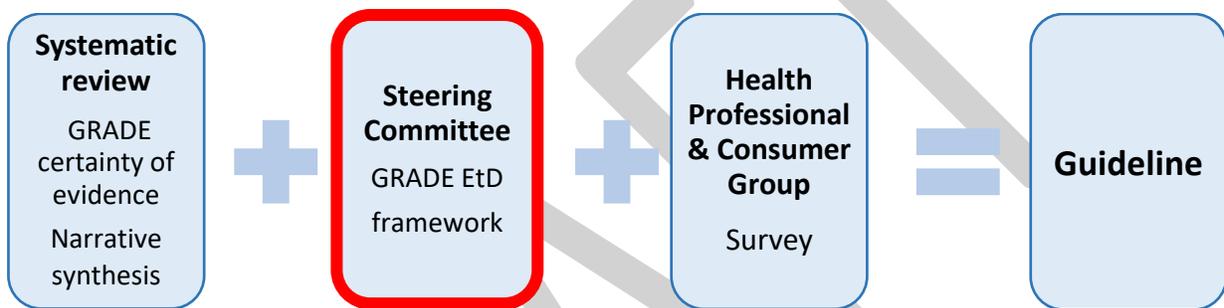
Outcome	Summary of key findings (narrative)
<b>Communication</b>	<p>Communication difficulties were frequently reported in children diagnosed with CBTL. Difficulties were seen across both speech and language. Post-operative Cerebellar Mutism Syndrome (pCMS) and/or dysarthria has been identified in children with brain tumours located in the posterior fossa.<sup>10-26,44,45,47-50,52,53,56,57,66</sup> Some studies have reported mutism resolving to dysarthria and/or language difficulties in these children, in particular.<sup>15,17,21,23,25,45,47,56,57</sup> Specific speech difficulties described in children diagnosed with brain tumour include: prosody differences,<sup>13,14,44-46</sup> poor articulation,<sup>13-15,22,44,46,52</sup> reduced intelligibility<sup>14,22</sup> and slow speech rate.<sup>15,22,44,45</sup> Voice problems (e.g. hoarseness, decreased pitch variation/monopitch, roughness, breathiness, instability, hypernasality and tremor)<sup>13-15,22,25,44,52,58,66</sup> and fluency problems<sup>16,46,52</sup> have also been identified in children diagnosed with brain tumours. To date, only two studies have reported speech difficulties in children with leukaemia,<sup>54,58</sup> 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,<sup>29,31,36,38-40,42,44-49,51-54,56-58</sup> word-finding difficulties,<sup>36,45,47</sup> discourse level (narrative) difficulties<sup>28</sup> and high-level language difficulties.<sup>30,31,37-40,42</sup> Literacy (reading, writing and spelling) has also been identified as an area of difficulty.<sup>27,30,31,35,41,44,52</sup> The evidence also highlighted that speech and language difficulties can co-occur in children with CBTL.<sup>44,46,48,49,51-54,58</sup> The incidence of communication difficulties varied across the literature and therefore a reliable indicator of prevalence could not be reported.</p>
<b>Swallowing</b>	<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).<sup>21,58,62</sup> Aspiration<sup>63,64</sup> and supplemental feeding during the oncology treatment phase has been reported.<sup>11,21,58,61,62</sup> 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.<sup>11,21,59,61,62</sup> 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 al, in preparation<sup>3</sup>

# 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.<sup>67</sup> 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).

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

## 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.<sup>67</sup> 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.<sup>68</sup>

### 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 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.

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Table 9. GRADE evidence to decision framework and summary of judgements: Communication

**GRADE EtD framework: Communication**

<b>Assessment/intervention for communication compared to no assessment/intervention for communication for children diagnosed with CBTL</b>	
<b>Population:</b>	Children aged 0-16 years old diagnosed with CBTL
<b>Prognostic Factors:</b>	Any type of childhood brain tumour or leukaemia
<b>Outcome measures:</b>	Speech and/or language measures
<b>Timing:</b>	Any (At diagnosis/pre-treatment, oncology treatment phase, oncology follow-up phase, survivorship phase)
<b>Setting:</b>	Any (inpatient or outpatient)
<b>Perspective:</b>	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).
<b>Background:</b>	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.

<b>Problem</b> <b>Is the problem a priority?</b>	
Judgement <sup>a</sup>	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ No</li> <li>○ Probably no</li> <li>○ Probably yes (3/9)</li> <li>• <b>Yes (6/9)</b></li> <li>○ Varies</li> <li>○ Don't know</li> </ul>	<p>“Interferes with skill development at social, educational level”</p> <p>“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”</p> <p>“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)”</p> <p>“Other impairments often take priority such as balance and tremor, however if not looked for are often overlooked”.</p> <p>“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”</p> <p>“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”</p> <p>“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”</p> <p>“A moderate priority in the overall scheme”</p> <p>“Without communication children cannot express themselves when needed”</p>

<b>Desirable Effects</b> <b>How substantial are the desirable anticipated effects?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ Trivial</li> <li>○ Small</li> <li>○ Moderate</li> <li>● <b>Large (8/9)</b></li> <li>○ Varies (1/9)</li> <li>○ Don't know</li> </ul>	<p>“Should be part of multidisciplinary care. Measure to assess, protect and enhance patient's skills and potential are highly valued priorities”</p> <p>“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”</p> <p>“Early diagnosis of communication problems (or not) a key way to assist children longer term”</p> <p>“Social interactions and learning in the classrooms are largely dependent on language so benefits likely to be large”</p> <p>“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.)”</p> <p>“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”</p> <p>“If you could achieve significant communication improvements, this would have substantial and desirable effects for the child”.</p> <p>“With the ability to communicate children will be able to advocate for their own health and wellbeing, let alone enjoy a more fulfilled life”</p>
<b>Undesirable Effects</b> <b>How substantial are the undesirable anticipated effects?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ Large (1/9)</li> <li>○ Moderate</li> <li>● <b>Small (4/9)</b></li> <li>○ Trivial (2/9)</li> <li>○ Varies 1/9)</li> <li>○ Don't know</li> </ul>	<p>“Potential stigmatisation, depends on co-existent morbidities/behavioural issues, parents' priorities”</p> <p>“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 &amp; families is likely considerable, as is the potential burden on society”</p> <p>“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)”</p> <p>“Perhaps related to anger or frustration in the child facing his/her communication deficits”</p>

	<p>“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”</p> <p>“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”</p> <p>“Without an ability to communicate, there could be grave impacts on a child's health status”</p>
<p><b>Certainty of evidence</b>  <b>What is the overall certainty of the evidence of effects?</b></p>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>• <b>Very low</b></li> <li>○ Low</li> <li>○ Moderate</li> <li>○ High</li> <li>○ No included studies</li> </ul>	See Tables 4-6 for GRADE certainty of evidence for communication outcomes (sub-divided into speech, language, speech+language)

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<b>Values</b> <b>Is there important uncertainty about or variability in how much people value the main outcomes?</b>	
Judgement	Steering Committee (Panel) Discussion
<input type="radio"/> Important uncertainty or variability <input checked="" type="radio"/> <b>Possibly important uncertainty or variability</b> (5/9) <input type="radio"/> Probably no important uncertainty or variability <input type="radio"/> No important uncertainty or variability (2/9) <input type="radio"/> Don't know (2/9)	<p>"Communication- most important. Enables interaction. Provides external measure of self-worth. Enables adaptation and behaviour change"</p> <p>"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"</p> <p>"Value of communication (esp. higher level skills) varies greatly - with some families and children valuing it highly"</p> <p>"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"</p> <p>"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)?"</p> <p>"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"</p> <p>"Some people might value communication intervention differently, although I think few would disagree that communication skills are foundational for children's wellbeing"</p>
<b>Balance of effects</b> <b>Does the balance between desirable and undesirable effects favor the intervention or the comparison?</b>	
Judgement	Steering Committee (Panel) Discussion
<input type="radio"/> Favors the comparison <input type="radio"/> Probably favors the comparison <input type="radio"/> Does not favor either the intervention or the comparison <input type="radio"/> Probably favors the intervention <input checked="" type="radio"/> <b>Favors the intervention</b> (8/9) <input type="radio"/> Varies <input type="radio"/> Don't know (1/9)	<p>"Dependent on individual patient and priorities within families. Overall intervention provides opportunities to vulnerable population"</p> <p>"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"</p> <p>"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)"</p> <p>"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"</p> <p>"The benefits in the short and long term of providing appropriate, timely communication assessment and intervention outweigh the possible undesirable effects"</p> <p>"I expect potential harms would be massively outweighed by potential benefits"</p>

<b>Resources required</b> <b>How large are the resource requirements (costs)?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ Large costs</li> <li>○ Moderate costs (2/9)</li> <li>○ Negligible costs (2/9)</li> <li>● <b>Costs and savings (3/9)</b></li> <li>○ Moderate savings (1/9)</li> <li>○ Large savings</li> <li>○ Varies</li> <li>○ Don't know</li> </ul>	<p>"Requires individualized approach. ROI hard to ascertain/measure"</p> <p>"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"</p> <p>"Cost of employing speech pathologists high short term, but longer term likely to be cost saving (to health, NDIS, family)".</p> <p>"Provides opportunity for early intervention to minimise later larger problems or misunderstandings"</p> <p>"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)"</p> <p>"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"</p> <p>"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"</p> <p>"Surely with the implementation of technology, this would not incur a huge cost"</p> <p>"More efficient healthcare provided if a child can advocate for themselves"</p>
<b>Certainty of evidence of required resources</b> <b>What is the certainty of the evidence of resource requirements (costs)?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ Very low</li> <li>○ Low</li> <li>○ Moderate</li> <li>○ High</li> <li>● <b>No included studies</b></li> </ul>	

<b>Cost effectiveness</b>	
<b>Does the cost-effectiveness of the intervention favor the intervention or the comparison?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ Favors the comparison</li> <li>○ Probably favors the comparison</li> <li>○ Does not favor either the intervention or the comparison</li> <li>○ Probably favors the intervention (3/9)</li> <li>• <b>Favors the intervention</b> (5/9)</li> <li>○ Varies</li> <li>○ Don't know (1/9)</li> </ul>	<p>“Enhances subsequent opportunities for patient in terms of skill/knowledge acquisition. Potentially neutralises or diminishes psychological stress in parents, family members”</p> <p>“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”</p> <p>“Need cost benefit studies in this field”</p> <p>“There would be an initial cost but in the longer-term providing this early communication intervention would be cost effective”</p> <p>“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”</p>

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<b>Equity</b>	
<b>What would be the impact on health equity?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ Reduced</li> <li>○ Probably reduced (1/9)</li> <li>○ Probably no impact</li> <li>○ Probably increased (2/9)</li> <li>• <b>Increased (6/9)</b></li> <li>○ Varies</li> <li>○ Don't know</li> </ul>	<p>“[Equity increased] not only for disadvantaged families/pts, also those from different cultures/non-English speaking background”</p> <p>“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”</p> <p>“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”</p> <p>“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”</p> <p>“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”</p> <p>“It would ensure a more just approach to all and provide inclusivity regardless of status etc...”</p> <p>“At present there are no guidelines limiting equity of access”</p>
<b>Acceptability</b>	
<b>Is the intervention acceptable to key stakeholders?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ No</li> <li>○ Probably no</li> <li>○ Probably yes (1/9)</li> <li>• <b>Yes (6/9)</b></li> <li>○ Varies</li> <li>○ Don't know (2/9)</li> </ul>	<p>“Highly valued”</p> <p>“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”</p> <p>“Brain tumors are complex and can impact all aspects of function and participation so should be very acceptable”</p> <p>“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”</p> <p>“I don't think many people would find it unacceptable”</p>

<b>Feasibility</b>	
<b>Is the intervention feasible to implement?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ No</li> <li>○ Probably no</li> <li>○ Probably yes (2/9)</li> <li>• <b>Yes (6/9)</b></li> <li>○ Varies (1/9)</li> <li>○ Don't know</li> </ul>	<p>“Should be part of initial assessment just as we currently assess psychosocial needs”</p> <p>“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”</p> <p>“It is feasible but \$\$\$ to employ SLPs needed across the country (not just city)”</p> <p>“Depends on staffing and funding”</p> <p>“Depends, among others, on geographical distance between caregivers and patients, and on Tele-facilities”.</p> <p>“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”</p> <p>“Apart from staff time, I don't anticipate any major barriers to implementation”</p> <p>“Communication is fundamental”</p> <p>“These are basic practices applied in other acute and chronic care settings”</p>

<sup>a</sup>The most frequently identified judgement is bolded, tallies of judgements are included in brackets

## Summary of judgements: Communication

	Judgement						
<b>Problem</b>	No	Probably no	Probably yes	Yes		Varies	Don't know
<b>Desirable Effects</b>	Trivial	Small	Moderate	Large		Varies	Don't know
<b>Undesirable Effects</b>	Large	Moderate	Small	Trivial		Varies	Don't know
<b>Certainty of evidence</b>	Very low	Low	Moderate	High			No included studies
<b>Values</b>	Important uncertainty or variability	Possibly important uncertainty or variability	Probably no important uncertainty or variability	No important uncertainty or variability			
<b>Balance of effects</b>	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
<b>Resources required</b>	Large costs	Moderate costs	Negligible costs	Costs and savings	Savings	Varies	Don't know
<b>Certainty of evidence of required resources</b>	Very low	Low	Moderate	High			No included studies
<b>Cost effectiveness</b>	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
<b>Equity</b>	Reduced	Probably reduced	Probably no impact	Probably increased	Increased	Varies	Don't know
<b>Acceptability</b>	No	Probably no	Probably yes	Yes		Varies	Don't know
<b>Feasibility</b>	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.**

## Type 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
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>

Table 10: GRADE Evidence to Decision framework and summary of judgements: Swallowing

**GRADE EtD framework: Swallowing**

<b>Assessment/management for swallowing compared to no assessment/management for swallowing for children diagnosed with CBTL</b>	
<b>Population:</b>	Children aged 0-16 years old diagnosed with CBTL
<b>Prognostic Factors:</b>	Any type of childhood brain tumour or leukaemia
<b>Outcome measures:</b>	Swallowing measures
<b>Timing:</b>	Any (At diagnosis/pre-treatment, oncology treatment phase, oncology follow-up phase, survivorship phase)
<b>Setting:</b>	Any (inpatient or outpatient)
<b>Perspective:</b>	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).
<b>Background:</b>	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.

<b>Problem</b> <b>Is the problem a priority?</b>	
Judgement <sup>a</sup>	Steering Committee (Panel) Discussion
<input type="radio"/> No <input type="radio"/> Probably no <input type="radio"/> Probably yes (3/9) <input checked="" type="radio"/> <b>Yes</b> (6/9) <input type="radio"/> Varies <input type="radio"/> Don't know	<p>"Nutritional issues, acute health care concerns, independence, social interaction, schooling, fitting in with peers, appearance"</p> <p>"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"</p> <p>"Potentially life threatening, plus impact on quality of life"</p> <p>"Depends on symptoms at the bedside, clinicians need to know to think about swallowing as much as they think about temperature post-op"</p> <p>"It will help detect inconspicuous problems, and, thus, reduce the frequency of untreated difficulties"</p> <p>"Definitely yes in the short-term due to potentially life-threatening problems if swallowing is not prioritised"</p> <p>"For children with a swallowing difficulty it is clearly a priority, but it possibly is less common and less long lasting than communication difficulties"</p> <p>"There is a need for all children"</p> <p>"It is a priority but not all children have swallowing challenges -it depends more on the site of the tumour"</p>
<b>Desirable Effects</b> <b>How substantial are the desirable anticipated effects?</b>	
Judgement	Steering Committee (Panel) Discussion
<input type="radio"/> Trivial <input type="radio"/> Small <input type="radio"/> Moderate (2/9) <input checked="" type="radio"/> <b>Large</b> (7/9) <input type="radio"/> Varies <input type="radio"/> Don't know	<p>"Assessments should be part of multidisciplinary care"</p> <p>"These cannot be understated. Imperative that swallowing is assessed and treated without delay, due to the significant consequences if left untreated"</p> <p>"Given the potential impact of dysphagia, the desirable effects of ensuring safe swallowing are important"</p> <p>"Prevent aspiration, safe swallowing of fluids and solids"</p> <p>"Potentially life-saving. Crucial for safe swallowing"</p> <p>"Swallowing intervention would be very important for those children experiencing difficulties"</p> <p>"Reducing aspiration risk is important to prevent onset of pneumonia or chest infections and other complications that would have negative impacts on health"</p>

<b>Undesirable Effects</b> <b>How substantial are the undesirable anticipated effects?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ Large (2/9)</li> <li>○ Moderate (1/9)</li> <li>• <b>Small</b> (3/9)</li> <li>○ Trivial (2/9)</li> <li>○ Varies</li> <li>○ Don't know (1/9)</li> </ul>	<p>“Highly valued”</p> <p>“No undesirable effects if swallowing assessment/treatment offered, in comparison to substantial life-threatening and impacting outcomes if not”</p> <p>“Given that swallowing assessment is normally brief, the negative effects relate mainly to anxiety”</p> <p>“Aspiration pneumonia can be an expensive complication of brain tumor treatment”</p> <p>“May be some stress on child and family”</p> <p>“I don't anticipate any undesirable effects, apart from impact on staff time and burden on families for the intervention”</p> <p>“Listen to the consumer- parents often know best about their child”</p> <p>“Aspiration due to swallowing difficulties could cause chest infections or pneumonia and gravely impact health for children who are already very unwell”</p>
<b>Certainty of evidence</b> <b>What is the overall certainty of the evidence of effects?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>• <b>Very low</b></li> <li>○ Low</li> <li>○ Moderate</li> <li>○ High</li> <li>○ No included studies</li> </ul>	<p>See Table 7 for GRADE certainty of evidence</p>

<b>Values</b>	
<b>Is there important uncertainty about or variability in how much people value the main outcomes?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ Important uncertainty or variability</li> <li>○ Possibly important uncertainty or variability (3/9)</li> <li>○ Probably no important uncertainty or variability (2/9)</li> <li>• <b>No important uncertainty or variability (4/9)</b></li> </ul>	<p>“Eating is a major social interaction which helps to bind relationships. Assessment and potential subsequent intervention - important and valued”</p> <p>“Importance of assessing and managing swallowing disorders well established”</p> <p>“Often not considered. Speech and OT and PT need to be part of the post op care of children with brain tumors or leukaemia”</p> <p>“This depends, among others, on how well informed they have been, as well as on their possible previous experiences”</p> <p>“I think all would value it highly”</p> <p>“Some health professionals may disagree about how important swallowing is if most of their patients do not have difficulties”</p> <p>“Swallowing - or rather - risks of swallowing disorder(s) -are poorly understood</p>

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<b>Balance of effects</b>	
<b>Does the balance between desirable and undesirable effects favor the intervention or the comparison?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ Favors the comparison</li> <li>○ Probably favors the comparison</li> <li>○ Does not favor either the intervention or the comparison</li> <li>○ Probably favors the intervention (4/9)</li> <li>• <b>Favors the intervention (5/9)</b></li> <li>○ Varies</li> <li>○ Don't know</li> </ul>	<p>“As stated, imperative that swallowing assessment/management is offered. The risks are too substantial if it is not”</p> <p>“Ensuring that children with CBTL are safe is important with minimal negative effect”</p> <p>“Needs more information to support a stronger recommendation but the gut feeling is likely to favour”</p> <p>“Benefits definitely outweigh undesirable effects”</p> <p>“Swallowing assessment/intervention would be valuable for children who have difficulty in this area”</p> <p>“All assessments have merit for children who are dealing with these cancers”</p> <p>“Prevention of pneumonia is important”</p>
<b>Resources required</b>	
<b>How large are the resource requirements (costs)?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ Large costs</li> <li>○ Moderate costs (1/9)</li> <li>• <b>Negligible costs (6/9)</b></li> <li>○ Costs and savings</li> <li>○ Moderate savings</li> <li>○ Large savings</li> <li>○ Varies</li> <li>○ Don't know (2/9)</li> </ul>	<p>“Important for independence, socialising, playing, and self-esteem”</p> <p>“Negligible resources required for a substantial positive outcome; and an intolerable outcome if not offered”</p> <p>“Note that although speech pathologists are highly skilled to provide swallowing assessment, others can be trained to assist with intervention plans”</p> <p>“Needs analysis”</p> <p>“Resources to provide swallowing assessment and mxment 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”</p> <p>“I expect health professional time will again be the primary resource needed”</p> <p>“A clear need has been mentioned”</p> <p>“A brief swallowing assessment with careful recommendations made by and SLP need not be time consuming”</p>

**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**



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<p><b>Cost effectiveness</b></p> <p><b>Does the cost-effectiveness of the intervention favor the intervention or the comparison?</b></p>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ Favors the comparison</li> <li>○ Probably favors the comparison</li> <li>○ Does not favor either the intervention or the comparison</li> <li>○ Probably favors the intervention (2/9)</li> <li>• <b>Favors the intervention</b> (6/9)</li> <li>○ Varies</li> <li>○ Don't know (1/9)</li> </ul>	<p>"Should be part of multidisciplinary assessment and support"</p> <p>"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"</p> <p>"Needs research"</p> <p>"Definitely cost effective to provide as it outweighs potential costs of swallowing problems and flow-on effects (e.g, aspiration then pneumonia)"</p> <p>"I'm not sure of the evidence in this area"</p> <p>"As it will assist in the long term journey of the child affected"</p> <p>"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"</p>
<p><b>Equity</b></p> <p><b>What would be the impact on health equity?</b></p>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ Reduced</li> <li>○ Probably reduced (1/9)</li> <li>○ Probably no impact</li> <li>○ Probably increased (1/9)</li> <li>• <b>Increased</b> (5/9)</li> <li>○ Varies</li> <li>○ Don't know (2/9)</li> </ul>	<p>"[Equity increased] for NESB patients/families and socially/financially disadvantaged groups"</p> <p>"Offering swallowing assessment/management to all children will ensure an equitable approach for all children"</p> <p>"need more data"</p> <p>"As per communication, a national guideline mandating minimum swallowing ax/mx would ensure all kids have access and thus improve equity"</p> <p>"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"</p> <p>"All would be able to access this assessment in a just way"</p> <p>"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"</p>

<b>Acceptability</b>	
<b>Is the intervention acceptable to key stakeholders?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ No</li> <li>○ Probably no</li> <li>○ Probably yes (1/9)</li> <li>• <b>Yes (7/9)</b></li> <li>○ Varies</li> <li>○ Don't know (1/9)</li> </ul>	<p>“Crucial component of supportive care”</p> <p>“As the risks and negative outcomes associated with not providing swallowing assessment/intervention are not acceptable”</p> <p>“Likely to be acceptable to most”</p> <p>“[yes] obvious”</p> <p>“Yes - MDT team members would find it acceptable and necessary. Families may need education on its importance before accepting it”</p> <p>“I expect it would be acceptable”</p> <p>“Evidence based”</p> <p>“The assessment and interventions for dysphagia should be acceptable”</p>
<b>Feasibility</b>	
<b>Is the intervention feasible to implement?</b>	
Judgement	Steering Committee (Panel) Discussion
<ul style="list-style-type: none"> <li>○ No</li> <li>○ Probably no</li> <li>○ Probably yes (1/9)</li> <li>• <b>Yes (6/9)</b></li> <li>○ Varies (2/9)</li> <li>○ Don't know</li> </ul>	<p>“Part of MDT assessment when providing comprehensive care to children with cancer and their families”</p> <p>“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”</p> <p>“Easy to implement as long as there are SLPs”</p> <p>“Depends on staffing and funding”</p> <p>“Depends, among others, on geographical distance between caregivers and patients, and on Tele-facilities”</p> <p>“As per communication, these children already have contact with major children hospital so feasible for them to provide in both short and longer-term”</p> <p>“It might depend on the resources available at each children's hospital”</p> <p>“Again - brief swallowing assessment is not onerous and just relies on SLP time”</p>

<sup>a</sup>The most frequently identified judgement is bolded, tallies of judgements are included in brackets

## Summary of judgements: Swallowing

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

## Recommendation

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

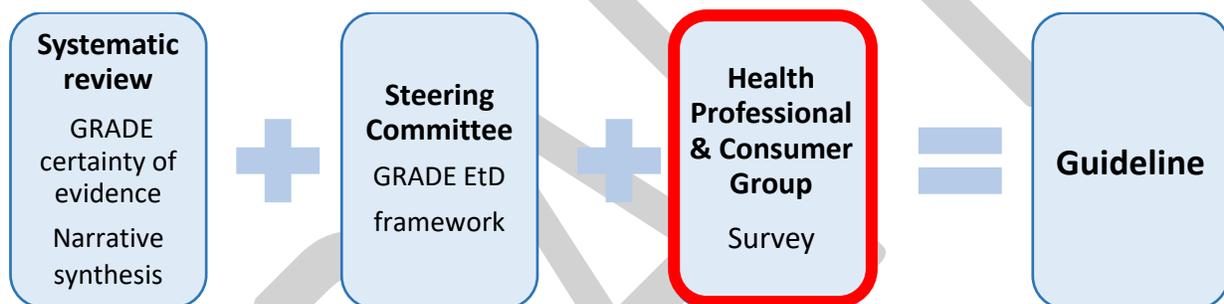
## Type of recommendation

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. 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 al, in preparation<sup>69</sup>). The methods and results of the Health Professional and Consumer Group survey are detailed below.

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

## Survey methods

### Participant recruitment

Multi-disciplinary 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).

Figure 11. Health professional recruitment



Figure 12. Consumer (parents and survivors) recruitment



<sup>a</sup>Australian and New Zealand Children's Haematology/Oncology Group

<sup>b</sup>Cancer organisations contacted: RedKite, Canteen, Cancer Council and the Childhood Cancer Association

## 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 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.

## 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.

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

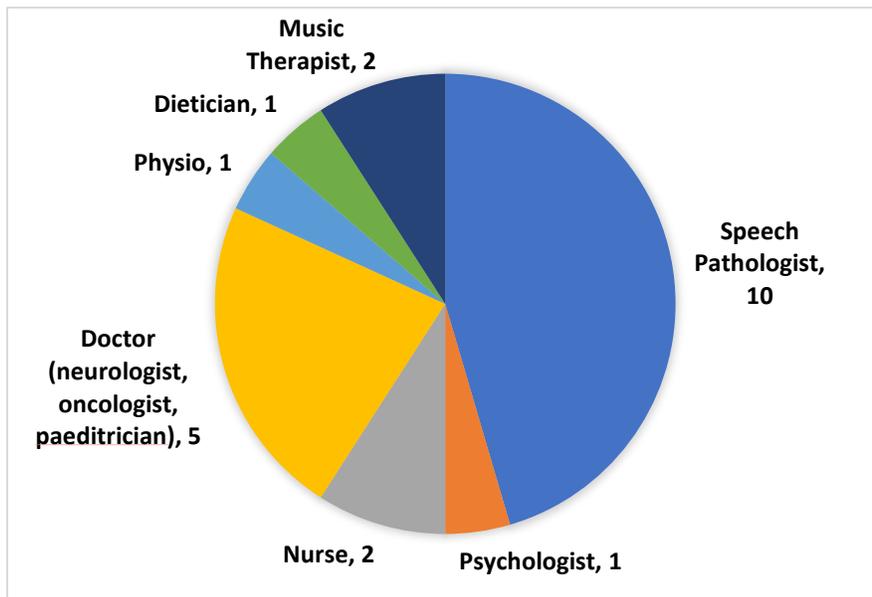
- Used for open-ended questions
- Identification of themes and sub-themes using Grounded theory

## 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.

Figure 14. Occupations of health professionals who completed the survey



## 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 individualized, dependent on patient factors and/or other risk factors. The role of monitoring communication skills via methods 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 multi-disciplinary team (MDT) approach to clinical management for children diagnosed with CBTL was recognized 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). Dieticians 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 (Chami et al, in preparation<sup>69</sup>)

<b>MDT Member</b> MDT member tally (n), percentage of total participants (N = 24)	<b>Sample Quotes</b>
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”
Pediatrician 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 al, in preparation<sup>69</sup>)

<b>MDT Member</b> MDT member tally (n), percentage of total participants (N = 24)	<b>Sample Quotes</b>
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 ...”
Dietician 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).” “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 “
Pediatrician n = 3, 13%	“Provides care coordination, provides education and support to staff, patient, parents and carers”

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## 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. SES)
- 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

#### **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 al, in preparation<sup>69</sup>

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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 Phoniatics
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: 15<sup>th</sup> June, 2018 (re-run 21<sup>st</sup> 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))

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## Embase

Platform: OvidSP

Database coverage: 1947-present

Date completed: 15<sup>th</sup> June, 2018 (re-run 21<sup>st</sup> 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 grammar* 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>))

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## CINAHL

Platform: EbscoHost

Database coverage: 1982-present

Date completed: 15<sup>th</sup> June, 2018 (re-run 21<sup>st</sup> 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 articulat* 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: 15<sup>th</sup> June, 2018 (re-run 21<sup>st</sup> 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 gramma\* 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.



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LABORATORY

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



Images/graphics in mock-up form only

**Dissemination Plan**  
**Draft for Public Consultation – July 13, 2020**

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# Dissemination Plan

## Guideline Purpose

The *'Clinical Practice Guideline for the Management of Communication and Swallowing in Children diagnosed with Childhood Brain Tumour or Leukaemia'* was developed to address the need for a systematic, evidence-based approach to the management of communication and swallowing in children diagnosed with childhood brain tumour or leukaemia (CBTL). It aims to assist health professionals to provide and advocate for evidence-based care and management of communication and swallowing in children diagnosed with CBTL. It also aims to educate patient consumers (parents of children with CBTL, survivors of CBTL) and support them to advocate for best practice management of communication and swallowing difficulties.

The intended outcome of this Guideline is to improve quality of life for children surviving brain cancer and leukaemia. This has involved translating evidence from the research and clinical/consumer expertise into recommendations that will guide improvements in cancer services and quality of clinical care for this population across Australia and worldwide.

The implementation of the evidence-based recommendations will result in a systematic and equitable approach to clinical management for communication and swallowing in CBTL, including long-term follow-up. This Guideline will also form the basis for targeted early intervention program development and survivorship surveillance planning. These recommendations will support children to keep healthy and lead a fulfilled life, not only during cancer diagnosis and treatment, but critically after cancer survival.

## Intended end users of the Guideline

This Guideline has been developed to provide evidence-based recommendations for Speech Pathologists and multidisciplinary health professionals involved in the management of communication and swallowing difficulties for children diagnosed with childhood brain tumour or leukaemia. It is to be used alongside clinician judgement and patient preferences. It is based on the best evidence available at the time of publication. Additional relevant health professionals may include, but are not limited to, Oncologists, Rehabilitation Physicians, Nurses, Occupational Therapists, Physiotherapists, Child Life and Music Therapists. It is also intended that education providers in educational settings will also access the

Guideline and recommendations in order to support CBTL survivors to transition back into the classroom and school community for educational services.

These recommendations will equip parents and families as lifelong advocates in seeking optimal quality of life outcomes for their children, by providing knowledge about issues their child may likely experience and what these might look like. This will ensure families can be connected with timely management, early intervention services and appropriate referral services. It is important that parents do not feel isolated or lost to follow-up, or do not feel inadequately prepared for their child's future.<sup>1</sup> This cohesive source of information about long-term communication and swallowing management will serve to guide survivors and their families to partner with health professionals where necessary to ensure improved quality of life outcomes for communication and swallowing.

## Objective

The aim of this plan is to disseminate Guideline recommendations nationally and internationally, and to engage in knowledge translation in the form of health professional training workshops, consumer workshops, and the development of multimedia educational resources in culturally and linguistically diverse formats to support implementation and dissemination. Implementation will focus on establishing access and eliminating barriers for children diagnosed with CBTL at risk of communication and swallowing difficulties and ensuring improved long-term quality of life outcomes. Targeted knowledge translation will aim to break down barriers for culturally and linguistically, socio-economically or geographically diverse communities, such as those in regional or remote areas. Implementation will also aim to reduce the long-term public health burden of children diagnosed with CBTL who are at-risk for communication and swallowing difficulties.<sup>2,3</sup> Outcomes will aim to see survivors, families, health care professionals, and educators better equipped to foresee and minimise disruption to communication development and swallowing abilities, including access to early intervention, and improved quality of life after cancer survival.<sup>4</sup>

## Dissemination and Knowledge Translation

Guideline implementation will focus on two phases: 1) Dissemination; and 2) Targeted knowledge translation. Knowledge translation and development of resources are currently funded by the Cancer Institute NSW and being lead by the Chair, Dr Kimberley Docking.

## Organisations responsible

The University of Sydney is responsible for dissemination and implementation of this Guideline in partnership with affiliation organisations of Steering Committee members; that is, the Cancer Centre for Children at The Children's Hospital at Westmead (CHW), the Kids Rehab Department at CHW; Murdoch Children's Research Institute; University of Melbourne; 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).

## Phase 1: Dissemination

### *Guideline Access*

Pending approval by NHMRC, the Guideline will be published and disseminated widely within 16 weeks of the approval date, in accordance with NHMRC publication requirements for Clinical Practice Guidelines. Once published the Guideline will be available via The University of Sydney website to download free of charge by the end user. The Guideline will also be included on NHMRC Clinical Practice Guidelines Portal and announced in NHMRC publications. Guideline recommendations will be accessible to key stakeholders throughout Australia and worldwide.

The published Guideline will be sent to all members of the Guideline Development Committee, including the Steering Committee and Health Professional and Consumer Group, for use and distribution by individuals and affiliation organisations. The online download link will also be sent to all organisations invited to provide comment during the public consultation period (Table 1), to be shared free of charge to their members and via their networks.

### *Scientific meetings and conferences*

The Guideline and recommendations will be presented at relevant national and international scientific and consumer conferences, such as Speech Pathology Australia national conference, ANZCHOG's Annual Scientific Meeting, Innovations in Cancer Treatment and Care Conference, International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Congress of the International Society of Paediatric Oncology (SIOP), Children's Oncology Group Annual Meeting, Australian Society for the Study of Brain Impairment (ASSBI), Posterior Fossa Society annual meeting, and the Ronald McDonald House Charities HELP (Health, Educators, Learners, Parents) conference.

Table 1. Organisations invited to comment during public consultation

American Speech and Hearing Association	Hunter Cancer Research Alliance
ANZCHOG (Australian and New Zealand Childrens Haematology/Oncology Group)	International Association of Logopedics and Phoniatics
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

*Peer-reviewed journal publications*

The systematic review of the literature, outcomes of the Health Professional and Consumer Group survey, and the Guideline methodology are being prepared for submission to high quality widely accessible peer-reviewed academic journals. These publications will cite the published Guideline. Outcomes of the systematic review, Health Professional and Consumer Group survey, and Guideline methodology papers will also be presented at national and international multidisciplinary and consumer conferences and seminars as outlined above.

### *Social media/ media channels*

The online link to the Guideline will be made available and shared on multiple relevant media and social media channels and platforms of The University of Sydney by the Lead Project Team, also facilitated by the Marketing and Communications (Medicine and Health) team at The University of Sydney. This will include social media, website, staff and University news, and other relevant media channels. The Guideline link will also be shared via health professional and consumer networks in the areas of speech pathology, paediatric oncology multidisciplinary teams, allied health, and to brain cancer and leukaemia consumer groups worldwide.

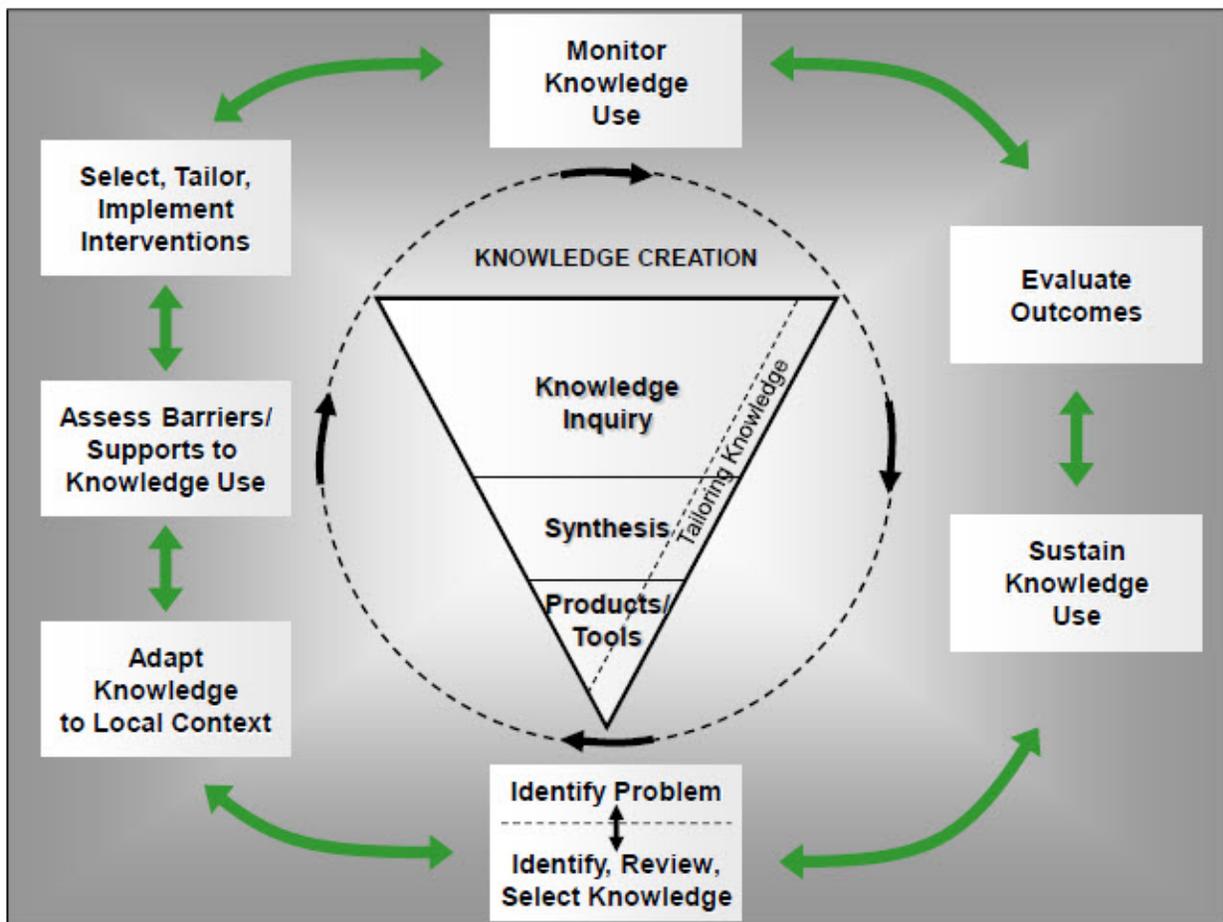
### *Phase 2: Implementation and knowledge translation*

Implementation and knowledge translation will be guided by the Knowledge-to-Action process<sup>5</sup> (Figure 1). This framework proposes a multifaceted approach to facilitate knowledge and information to become embedded into routine practice. This leads to the idea of 'knowledge' or information only forming one part of the solution. The model suggests starting with the identification of a problem, displayed in Figure 1 at the centre of the KTA model, and is broken down into knowledge inquiry, synthesis, developing products and tools. Therefore, Phase 2 will include development of resources to support implementation of Guideline evidence-based recommendations and key practice points, including summaries and online decision-making tools for multidisciplinary health care professionals across stakeholder and clinical settings, educational settings, and consumer organisations and groups in Australia and worldwide. Implementation will utilise information technology and educational multimedia to produce publicly available online information for intended end users about Guideline evidence-based recommendations and key practice points, including early assessment and intervention, management over time, risk factors, and appropriate support/referral services.

Inequitable and poor access to clinical cancer care pathways and cancer care services is a critical issue that can impact the long-term quality of life and survivorship of children diagnosed with CBTL, due to cultural and social diversity, and geographic location.<sup>2,3</sup> Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse (CALD) communities as well as families from socio-economically disadvantaged backgrounds often face unique challenges in regard to accessing cancer care services.<sup>2,3</sup> A rapid review commissioned by the Cancer Institute NSW<sup>3</sup> highlighted the importance of practical, educational and social support in improving cancer outcomes and achieving increased satisfaction for CALD populations. This review specified that the development of culturally appropriate interventions and programs should consider individual and cultural barriers to accessing health services.<sup>3</sup>

In Australia, there are over 300 separately identified languages spoken at home<sup>6-9</sup>. While English is the main language spoken, the most recent census data showed that 21% of Australians speak a language other than English at home<sup>6</sup>. In addition, 3.3% of the total Australian population is made up by Aboriginal and Torres Strait Islander people (798,400).<sup>8</sup> Accordingly, implementation will consider priorities of Aboriginal and Torres Strait Islander people and consumers from culturally and linguistically diverse communities and those at-risk of poorer outcomes. It will aim to minimise barriers to management of communication and swallowing for children diagnosed with CBTL in these populations; by providing recommendations and information in multiple accessible formats about, why and how to access services, and appropriate support/referral services.

Figure 1. Knowledge-to-Action (KTA) process. Source: Graham et al. (2006)<sup>5</sup>



Use of information technology to facilitate implementation is anticipated to bridge gaps in accessing and ensuring timely intervention for children diagnosed with CBTL and their families, and create awareness and education for children, families, education professionals in school settings, and multidisciplinary

health professionals. Educational multimedia resources will be developed in partnership with consumers (parents, children diagnosed with CBTL), Aboriginal and Torres Strait Islander people and representatives from culturally and linguistically diverse communities across Australia. Multimedia and educational resources will aim to deliver content specifically tailored to the needs, challenges and preferences of the most common culturally and linguistically diverse populations represented in Australia. Resources will be developed in formats designed for social media, as well as longer-format educational versions for access by consumers and parents on websites, in oncology ward family and waiting zones, outpatient clinics, allied health clinics, community health settings (including rural, regional, and remote), schools (professional development for teachers; Parents and Citizens (P&C) meetings; special education schools and settings), and community engagement and awareness programs.

Multimedia educational resources will also all be publicly available free of charge on a website designed and developed as a key outcome of implementation. The website will be available for viewing content in multiple languages (e.g. English, Arabic, Mandarin, Cantonese) representing some of the most common culturally and linguistically diverse communities in Australia, and will contain the educational multimedia resources. Links to social media platforms will also be available on the website for target intended end users, including parents/families/community members, to receive regular updates about communication development and swallowing difficulties for children diagnosed with CBTL at their current developmental level or in the future. The website will also contain a 'Frequently Asked Questions' (FAQ) section for common issues, developmental timepoints, schooling questions, when and where to access support, and referral information. The FAQ section will also contain information about local online forums and face-to-face support groups and services. Use of information technology will permit access to information, education, and support services for rural and regional families and users, culturally and linguistically diverse communities, and therefore at-risk children and families in this population.

Implementation has the potential for scalability throughout health and educational services across Australia and internationally via organisations affiliated with the development of the Guideline and/or invited to comment through the public consultation process. The aims and objectives are focused on implementation across Australia and internationally. Affiliation and partner organisations of the Guideline Development Committee members and key stakeholders will ensure scope and reach for sustainable outcomes across Australia well beyond the implementation funding period. Resources and materials developed will continue to be publicly available online free of charge for end users.

## Evaluation and outcome measures

The Knowledge-to-Action process<sup>5</sup> (Figure 1) will also be used to guide the approach and processes of evaluation. Dissemination of the Guideline will be measured, analysed and reported to enhance and ensure a cycle of improvement in practice and ultimately policy. Measurement of Guideline dissemination and change in satisfaction and knowledge of healthcare professionals, consumers, and organisations will occur via stakeholder (health professional and consumer) feedback surveys. Stakeholders will be surveyed pre- and 12 months post-Guideline dissemination and will be provided with an opportunity for feedback regarding integration of evidence-based recommendations into service contexts and contributions to management of communication and swallowing for children diagnosed with CBTL.

The development of the survey will be based on international tools designed to assess use of Guideline recommendations and factors related to their uptake in clinical practice.<sup>10</sup> Surveys will be developed using the software program, Qualtrics (<https://www.qualtrics.com/>). The online survey will consist of Likert scale ratings and free text area responses to gather qualitative comments or additional information. Questions may cover demographics and professional characteristics, such as age, discipline and years in practice; context and attitudes regarding Guideline evidence-based recommendations.<sup>11-13</sup> Questions will also assess resources, systems, and attitudinal barriers, as well as improving the use of the Guideline recommendations and will collect free-text comments to assist with revisions and the review processes of the Guideline. Between-group differences will be analysed, and potential predictors of Guideline use will be explored via logistic regression. The outcome measures follow-up survey at 12 months post implementation will determine progress made towards uptake of the recommendations, and therefore towards improving outcomes in this population.

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