



Clinical Practice Guideline

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


Dissemination & Implementation Plan





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Publication Approval



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

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Dissemination & Implementation 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.¹ 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.^{2,3} 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.⁴

Dissemination and knowledge translation

Guideline implementation will focus on two phases: 1) Dissemination; and 2) Targeted knowledge translation. Implementation and knowledge translation and development of resources are currently funded by the Cancer Institute NSW and being led 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

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 Phoniatrics
Association of Child Life Therapists Australia	Kids Cancer Alliance
Australian Medical Association	Kids Cancer Project
Australian Music Therapy Association	Leukaemia Foundation
Australian Physiotherapy Association	Occupational Therapy Australia
Australian Primary Healthcare Nurses Association	Pirate Ship Foundation

Australian Psychology Society

Posterior Fossa Society

Brain Tumour Alliance Australia

Red Kite

Cancer Australia

Ronald McDonald House Charities

Cancer Council Australia

Royal Australasian College of Physicians
(Paediatrics)

CanTeen

Speech Pathology Australia

Centre for Oncology Education and Research
Translation (CONCERT)

Starlight Children's Foundation

Childhood Cancer Association

Sydney Catalyst

Clinical Oncology Society of Australia

Sydney Vital

Consumers Health Forum of Australia

Sydney West Translational Cancer Research Centre

Cure Brain Cancer Foundation

The Royal College of Speech and Language
Therapists

Dietitians Association of Australia

Translational Cancer Research Network



Peer-reviewed journal publications

The systematic review of the literature has been published in a high quality widely accessible peer-reviewed journal,⁵ and outcomes of the Health Professional and Consumer Group have also been submitted.⁶ These publications cite the published guideline. Outcomes of the systematic review, and Health Professional and Consumer Group survey 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 Development 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 process⁷ (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.

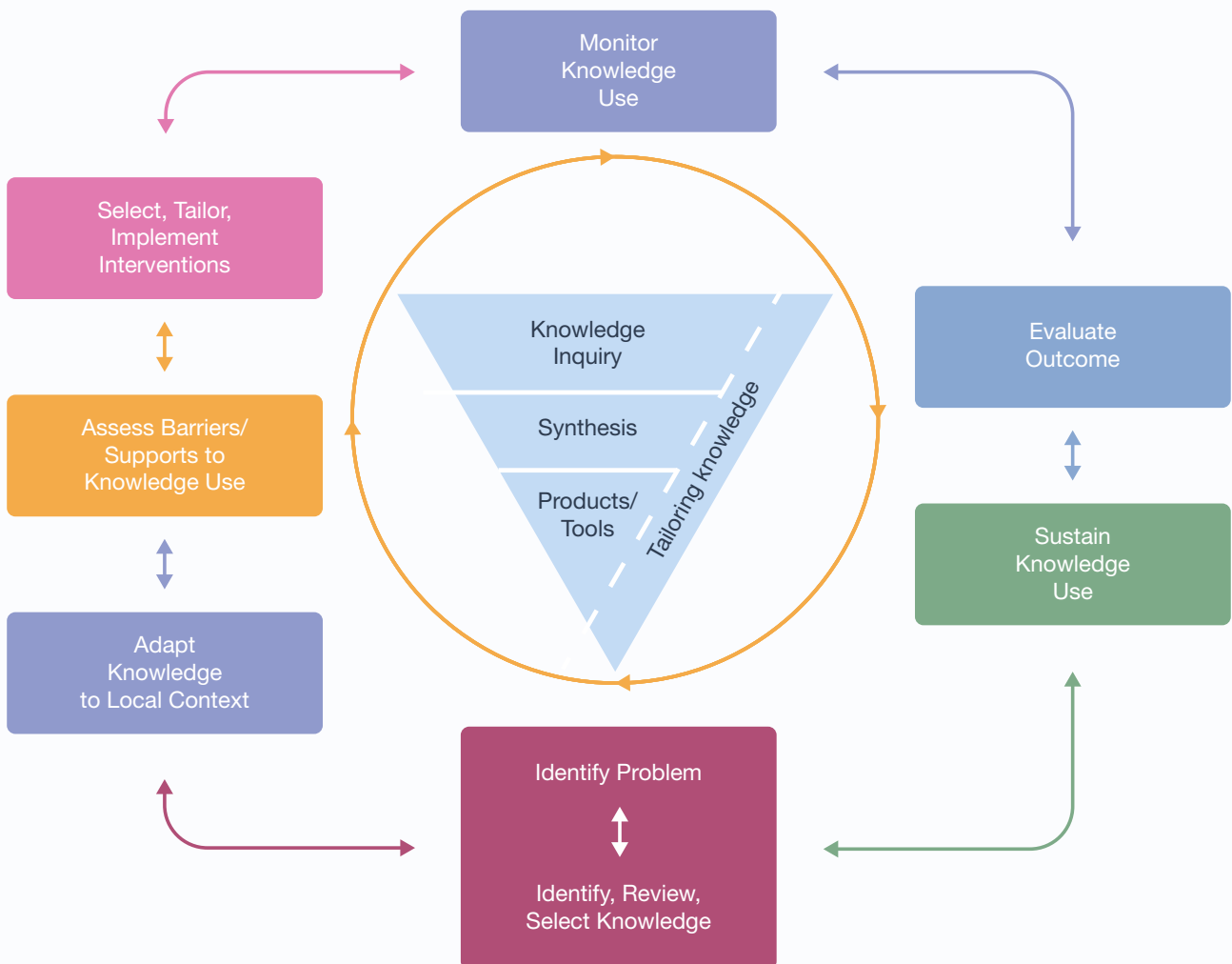
Inequitable and poor access to clinical cancer care pathways and cancer care services is a critical issue that can impact the long-term quality of life and survivorship of children diagnosed with CBTL, due to cultural and social diversity, and geographic location.^{2,3} Aboriginal and Torres Strait Islander 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.^{2,3} A rapid review commissioned by the Cancer Institute NSW³ 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.³ In Australia, there are over 300 separately identified languages spoken at home⁸⁻¹¹. While English is the main language spoken, the most recent census data showed that 21% of Australians speak a language other than English at home⁶. In addition, 3.3% of the total Australian population is made up by Aboriginal and Torres Strait Islander people (798,400)¹⁰. 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.

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

Figure 1
Knowledge-to-Action (KTA) process. Source: Graham et al⁷



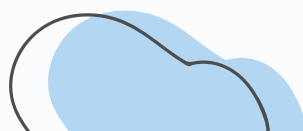


teachers; Parents and Citizens (P&C) meetings; special education schools and settings), and community engagement and awareness programs.

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 Guideline Summary will be available in multiple languages (e.g. English, Arabic, Mandarin, Cantonese, Italian, & Portuguese) 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 process⁵ (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.¹² 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.¹³⁻¹⁵ 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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