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# Management of communication and swallowing following childhood brain tumour and leukaemia: A survey of multidisciplinary health professionals and consumers

## **Who is conducting the research?**

The research is being conducted by Dr Kimberley Docking from the Faculty of Health Sciences, Department of Speech and Language Pathology, University of Sydney.

## **What is the research about?**

Childhood brain tumour and leukaemia are the most common types of cancer in children. These cancers and the cancer treatments can affect communication and swallowing and have a negative impact on their quality of life. Currently, there are no Clinical Practice Guidelines to guide health professionals involved in the care of children with difficulties in these areas. To address this need, we plan to develop a Clinical Practice Guideline for the Management of Communication and Swallowing Disorders following Childhood Brain Tumour and Leukaemia (CBTL). This will include recommendations about management, assessment and intervention. To do this we will form an Expert Panel, by asking health professionals who work in the field, and people who have survived CBTL or parents of CBTL survivors, to contribute.

By being part of this Expert Panel participants will be asked to complete a survey. This survey will allow us to gather insight into the care of individuals following Childhood Brain Tumour and Leukaemia (CBTL). We will collect and analyse these survey responses to form recommendations for the Clinical Practice Guideline.

## **How will it help children and young people with cancer and/or their families?**

The clinical guidelines will be used to guide health professionals in the care of children with difficulties in communication and swallowing as a result of brain tumour or leukaemia and cancer treatments. The purpose and aim of developing a set of standardised clinical practice guidelines is to improve equity of access to services for children with communication and swallowing disorders after childhood brain tumour and leukaemia. This aims to improve quality of life & communication outcomes for children surviving brain tumour and leukaemia.

## **Who can take part?**

Participants need to be either:

- 1) A parent of a child or adolescent who has survived childhood brain cancer or leukaemia; or
- 2) An adult who has survived childhood cancer or leukaemia; or
- 3) A health professional who has experience with children who have been diagnosed with childhood brain tumour and leukaemia.

Participants need to be able to independently provide consent. Participant will also need to have adequate reading, writing, and English skills to complete the survey on a computer online or by interview over the phone. A phone interview can also be organised with a member of the research team if preferred.

## **What will participants be asked to do?**

Participants who consent will be a member of the Expert Panel and will complete an online survey. This can be done on a computer/device or via phone interview. In this survey participants will be asked general demographic information about themselves, as well as their experiences in relation to management of communication and swallowing disorders in children following CBTL. Members of the Expert Panel will be acknowledged by name in the Clinical Practice Guideline and related materials, which will be published in the public domain. This is to acknowledge the contributions and also highlight the expertise behind the recommendations outlined in these guidelines.

This online survey will take around 30 minutes to complete. This could be longer or shorter for each individual. The survey does not have to be completed in one sitting, as it can be stopped and started as long as the same computer and same web browser are used.

## **When and where is the research taking place?**

The study is online and will be running until August 2022

## **Who has reviewed this study?**

This study has been reviewed by the University of Sydney Human Research Ethics Committee (Approval number 2018/507).

## **How to find out more**

If you would like to find out more about this study, please contact Dr Kimberley Docking (Speech Pathologist & Researcher) on (02) 9351 9694 or [kimberley.docking@sydney.edu.au](mailto:kimberley.docking@sydney.edu.au)

Please note that by asking for more information you are not committing yourself in any way.