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Symptoms and Side Effects: Defining Priorities in Cancer Symptoms for Paediatric, Adolescent and Young Adult Patients: An Australian/ New Zealand Modified Delphi Study

Who is conducting the research?

The research is being conducted by Professor Meera Agar and Dr Vanessa Yenson from the Cancer Symptom Trials (CST), Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT), through the Faculty of Health, University of Technology Sydney.

What is the research about?

The aim of this study is to identify and understand which symptoms and side effects of cancer and its treatment have the biggest impact on everyday life for children, young people and their families. Almost every person living with or after cancer will experience some symptom from the cancer itself or the related treatment, such as chemotherapy or radiotherapy. Children and young people will have different experiences compared to adults, and it is important that we investigate what these are. By identifying and understanding which symptoms and side effects trouble your child the most, we will be able to advocate for high quality research and more clinical trials into better ways to prevent, detect and manage these symptoms. The outcome will help improve the quality of life for children, young people and their families living with and after cancer.

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

Most young people diagnosed with cancer experience some symptoms or side effects from the treatment or the disease itself (such as chemotherapy or radiation). Cancer Symptom Trials (CST) researchers, in collaboration with paediatric and adolescent and young adult (AYA) specialists from around Australia and New Zealand, want to find out what the most troubling cancer symptoms are faced by young people in our region. These surveys and meetings will give young people diagnosed with cancer, their carers, and the healthcare professionals who treat them, a platform to voice their opinions on their experiences with cancer symptoms and discuss the treatments that work, as well as those they would like more research on. These results will inform our future research priorities, so we focus

research projects and clinical trials on the highest priority cancer symptoms for better detection, prevention, and management.

It is important to investigate cancer symptoms faced by young people separately to those experienced by adults. This is because young people face different types of cancers to adults. They also have different developmental needs and psychosocial pressures. Conventional treatments to alleviate symptoms go through high-quality clinical trials before coming onto the market, however these clinical trials are traditionally conducted with adults over the age of 18. This survey study will help us understand whether there are symptoms that remain troubling for children, adolescents, and young adults even with the best available current management and treatment.

Symptoms and side effects associated with cancer and its treatments are often seen as a given, with young people and their parents accepting and persevering through these because they are an expected part of the treatment and getting better. The outcomes of this survey study will highlight the most troubling cancer symptoms for children and young people. This will direct future research priorities to improve everyday quality of life for each child and young person diagnosed with cancer as well as their whole family and friend network.

Who can take part?

You can take part in this study if you...

- were diagnosed with cancer before the age of 25 (0 – 24 years old, inclusive)
- are a carer of someone diagnosed with cancer before the age of 25
- a healthcare professional who works with young people diagnosed with cancer before the age of 25
- a Parental /guardian consent is required for those under the age of 18
- Informed consent is required for those over the age of 18

What will participants be asked to do?

There are 3 planned rounds in this Delphi study. All stages are voluntary.

Round 1: Participants will be asked to complete an online survey with three main parts as listed below. If participants would like to take part in Round 2, they can leave their email address at the end Round 1 (email address is separate to all survey answers, which remain anonymous).

- Demographic information – to provide information on where they are, what type of cancer and what type of treatment they have received.
- Cancer symptom information – age-appropriate questions on which cancer symptoms they find the most troubling.

- Symptom treatment – to provide suggestions of treatments they think require further research.

Round 2*: Participants will be asked to complete an online survey, with questions derived from results from Round 1. If participants would like to take part in the meetings, they can leave their email address at the end Round 2 (email address is separate to all survey answers, which remain anonymous). This will likely ask participants to:

- Vote on the symptoms that were close to reaching 70% consensus from Round 1 (as important for further research or not)
- Vote on whether the symptom treatments raised in Round 1 are important (i.e. give it a score of low, medium, high importance)

Round 3: Zoom meetings will be conducted (patients and carers meetings will be separate to the healthcare professional meets) to vote on the symptoms and treatments raised in Rounds 1 and 2. It will give participants the freedom to discuss specific symptoms and treatments.

*Round 2 may not be necessary if consensus is high, or if participation has been low.

When and where is the research taking place?

The Round 1 survey is currently open. To find out more please go to <https://www.uts.edu.au/cst/cstprojects>

Who has reviewed this study?

This study has been reviewed by the Sydney Children's Hospital Network (SCHN) Human Research Ethics Committee.

How to find out more

If you would like to find out more about this study, please email CST@uts.edu.au

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