Research on *When Cancer Comes Along: CanTeen’s High School Educational Program*

Information sheet for parents and carers

**About the research project**
CanTeen Australia, the Australian Organisation for Young People Living with Cancer, is inviting your child to participate in a research project about the benefit of their high school educational program, *When Cancer Comes Along*.

We want to find out if this program improves young people’s understanding of cancer and its impact, including things they can do to reduce their risk of getting cancer. We also want to teach young people ways to help friends or other people they may know who are living with cancer. This information will be used to inform any further development and the nationwide roll out of the program.

Your school has elected for your child to take part in the program and the associated research project. We are asking you to let us know if you would **not** like your child to take part in this program.

Please take the time to read through this information about the program and research project. This will help you to make a decision about whether you would like your child to participate.

**What will the program involve?**

Staff members from CanTeen will visit your child’s school during class time to deliver the program. *When Cancer Comes Along* is an educational presentation that takes approximately 90 minutes. The learning objectives of the presentation are to:

- Provide your child with knowledge about cancer, including its signs/symptoms, risk factors and relevance to your child.
- Increase your child’s understanding of the impact a cancer diagnosis has on young people.
- Increase your child’s knowledge and confidence in applying skills of how to support somebody living with cancer.
- Increase your child’s knowledge of CanTeen and the services they offer.

**What will the research involve?**

Your child’s class or school will be randomly allocated to either get the program immediately, or to complete some questionnaires before getting the program. If your child’s class or school does not get the program immediately they will continue their regular class activities.

Your child will be asked to complete questionnaires at three time points: one week before they attend the program/regular class, immediately after they attend the program/regular class, and two months after they attend the program/regular class. Your child will complete the questionnaires during class time and each one will take approximately 20 minutes. Completing three questionnaires will help CanTeen to see if the program is useful for young people over time.
Each questionnaire will ask some questions about your child, what they know about cancer, how they think about things, and some of their regular health behaviours. At the end of the program your child will also be asked some questions about their opinions and satisfaction with the program. This will help CanTeen to check if the program is interesting and useful for young people.

**What if I don’t want my child to take part in the project?**
That’s OK. It is not compulsory. If you do not want your child to participate in the program or complete the questionnaires please fill out the form attached and return it to your child’s school, or to us. You can also contact the school directly or the researchers to let them know you do not want your child to participate. Your child has also been given an information sheet. Your child will let the school know if they are happy to fill out their questionnaires by completing a form attached to their first questionnaire booklet.

If you and your child decide to take part, you both have the right to withdraw from the project at any time, without having to provide a reason. There will be no impact on your or your child’s relationships with your child’s school or CanTeen if your child does not participate in this program or the research project.

**Can I or my child be identified as participants?**
No, you or your child will not be identified through the research project. We may use quotes in the final report, on our website or in other materials, but no names or identifying information will be used.

**Is there anything that might make my child upset if they take part?**
It is possible that discussing cancer and cancer experiences may be upsetting for your child. The facilitators of the program are experienced staff members who work with lots of young people affected by cancer. Your child can ask them for support if they feel distressed. Alternatively your child can speak to someone from their school (e.g., school counsellor).

The helplines below are also available for your child to contact if they have any worries or concerns about how they are feeling:

- **Kids HelpLine on 1800 55 1800.** The Kids HelpLine is a free, confidential and anonymous service for young people aged 5-25 years.
- **LifeLine on 13 11 14.** LifeLine is staffed by trained volunteer telephone counsellors who are available 24 hours a day, 7 days a week.
- **CanTeen’s Support Services: 1800 835 932.**

**What will happen to the information collected?**
Your child’s questionnaire information will be stored securely by CanTeen. Only the research team will have access to this information.

**What do I need to do?**
If you do not wish for your child to attend *When Cancer Comes Along,* CanTeen’s high school educational program or complete the associated questionnaires, please complete the attached form and return it to your child’s school before 14/03/19. Your child has also been given an information sheet.

If you have any questions about the project you can contact Steph Konings, Research Officer at CanTeen Australia on 1800 234 007.
Opt-out form for parents and guardians

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If you are happy for your child to attend *When Cancer Comes Along: CanTeen’s High School Educational Program*, you do not have to do anything.

**If you do not wish for your child to take part** in either the program or the questionnaires that are a part of the program, please fill out the sections below:

I do not wish for my child to attend *When Cancer Comes Along: CanTeen’s High School Educational Program*. [ ]

I do not wish for my child to complete the three sets of questionnaires as part of the research project evaluating CanTeen’s High School Educational Program. [ ]

Name: _______________________________________________________________

Signature: ___________________________________________________________________

Date: ___________________________________________________________________

Child’s name: ___________________________________________________________

Class: ___________________________________________________________________

School: ___________________________________________________________________

Please return this form to your child’s school, or send to Steph Konings, research officer:

CanTeen Australia
GPO Box 3821
Sydney NSW 2001

Alternatively, you can call direct on 1800 234 007, or email researchteam@canteen.org.au