Participant Information Sheet

Title

Teenagers and Young Adults with Cancer (TYAC) Good Practice Guide Development: How Healthcare Professionals can Communicate Effectively with Teenagers and Young Adults With Cancer

Invitation Paragraph

We are producing guidance for healthcare professionals to improve communication with young people with cancer. This is funded by TYAC, the UK's professional association for healthcare professionals caring for young people with cancer. As part of this we would value young people's input on examples of good and bad communication in a healthcare setting. We are therefore inviting you to complete a questionnaire related to your experiences of and preferences for communication with healthcare professionals. The link to the questionnaire is at the end of this document.

Purpose of the study

The purpose of the study is to produce a guideline that healthcare professionals can use to inform how they communicate with young people with cancer. Our aim is that this guideline enables healthcare professionals to empower young people to speak and be involved in decisions about their care to the level they want.

Why have I been chosen?

You have been chosen because you were diagnosed with cancer between the ages of 13-24 in the last five years. You must be at least 16 years old at the time you complete the questionnaire.

Do I have to take part?

You should only agree to complete the questionnaires if you want to, it is entirely up to you. If you choose not to take part this will not affect your care. Your clinical teams will not know if you have or have not taken part in this study.

Please read this entire information leaflet carefully before making your decision as to whether or not to take part. It will tell you why the research is being done and what you will be asked to do if you take part. Please contact us if there is anything that is not clear, or if you would like more information.

If you decide to take part, you will be asked to read an electronic consent form. Following this, continuation to the electronic questionnaire will acknowledge your consent and agreement to take part.

You can opt out by choosing not to complete the questionnaire. As the answers of the questionnaire are anonymous, once you have completed it, we will be unable to identify your answers and therefore cannot remove them.

What will happen to me if I take part?

The study involves completing a short online form. The information will identify what is good and bad communication when healthcare professionals are communicating with young people with cancer.

There will be a contact email address at the end of the questionnaire, in case you have any questions.

What do I have to do?

The study involves completing an electronic short questionnaire which should not take more than 30 minutes to complete.

Are there any possible disadvantages and or risks in taking part?

You will have to spend time filling in the questionnaire.

We are aware that you might find it uncomfortable reflecting back on previous experiences that may have been difficult for you at the time and continue to be challenging. Therefore participation in the study is entirely voluntary, and we can suggest sources of support should you need them.

What are the possible benefits of taking part?

Taking part in this research may not benefit you personally. However, being involved in the study will contribute to the understanding of what good communication with young people is. We can share this knowledge with healthcare professionals to enable them to develop better communication skills with young people and be confident and skilled communicators.

Will my taking part in this project be kept confidential?

Yes, all information will be kept strictly confidential because this is an anonymised study and data will be stored on a secure network drive. Any publications resulting from this research will be anonymous and your answers will be combined with the answers of other participants and will not be directly attributable to you. For further general information about how the University of Cambridge uses personal data please follow the link: https://www.information-compliance.admin.cam.ac.uk/data-protection/research-participant-data.

What will happen to the results of the research project?

Once the study is complete the results will be analysed and used to inform a Good Practice Guideline on Communicating with Young People with Cancer. The results will also be published as academic paper(s) in a peer-reviewed journal.

You can contact us if you wish to know more about the results and outcomes of the study.

Who is organising and funding the research?

This research is being funded by the national organisation for professionals – Teenagers and Young Adults with Cancer (TYAC) www.tyac.org.uk.
Award reference: TYAC GPG2021-2.

Ethical review of the study
The project has been reviewed by the University of Cambridge Psychology Research Ethics Committee.

Contact for further information.
If you have any questions about the study, please contact the researchers, Debbie Critoph by e-mail – dc625@medschl.cam.ac.uk or Dr Luke Smith – luke.smith35@nhs.net

Link to questionnaire: https://tinyurl.com/4dun525s