

## FREQUENTLY ASKED QUESTIONS

UK wide survey exploring the impact of young people's cancer on wellbeing, quality of life and needs of diagnosed individuals, and their parents/carers and siblings.

Young Lives vs Cancer, Teenage Cancer Trust, Children's Cancer and Leukaemia Group, and Ellen MacArthur Cancer Trust have launched this survey together, working with Dartington Service Design Lab.

These survey questions capture information about your wellbeing, quality of life and current needs. We are also collecting relevant demographic details to provide insight into the groups and communities affected by cancer.

**The purpose of this document is to ensure that potential participants understand the main points about taking part in this research and how to complete the survey.**

The research project's aims, and the approach have been reviewed and approved by the Chair of the Centre for Social Policy Ethics Committee, Roger Bullock. The processes involved within the research for collecting data, as well as the storing, usage deletion of personal data have been reviewed by the Data Protection Manager at Young Lives vs Cancer and Mark Burnett (Data protection advisor of Hope & May).

The lawful basis for data collection for the purpose of the survey is because it is necessary for the purposes of our legitimate Interests to support research, insights and development of services and delivery by Young Lives vs Cancer and project partners. The condition for processing special category data, where relevant, is because it is necessary for the purposes of scientific or historical research purposes in the public interest. We will be relying on the 'research provisions' of the UK General Data Protection Regulation (UK GDPR) when using personal data. If you have questions related to the survey, please contact the project lead Nate Sheach via email: [Nathan.sheach@dartington.org.uk](mailto:Nathan.sheach@dartington.org.uk).

### **What is the purpose of this research project?**

Young Lives vs Cancer and Dartington Service Design Lab are working in partnership to carry out research to better understand the experiences of people affected by cancer up to 10 years after the end of cancer treatment.

Respondents should be over the age of 14 and resident in the UK. The groups we are interested in hearing from are:

- 1. People who have been diagnosed with cancer at any point before the age of 25 and who have received cancer treatment in the last 10 years.**
- 2. Parents, carers or siblings of a person who was diagnosed with cancer before the age of 25 and who have received cancer treatment in the last 10 years.**

The research aims to understand the long-term impacts of young people's cancer on wellbeing, quality of life and needs across different populations and at different points beyond diagnosis. The research will help make cancer care of young people better in the future.

### **What will taking part in this research involve me doing in practical terms?**

The research will involve you completing the survey from a computer or mobile device, in surroundings in which you have privacy to respond to the different question areas.

The survey has six sections: screening questions related to diagnosis, current wellbeing, current quality of life, current needs, support provided during treatment and demographic questions about you.

You have the option throughout to select the option to “prefer not to say” or leave items blank if you are not comfortable responding to questions.

The survey takes around 15 minutes to complete. As the survey is completed anonymously, there is no log in required. This does mean that you must be able to complete your response in a single session.

There will be a One4all voucher as compensation available to the first 500 respondents for taking part in the survey, information for how to apply for this is available within the survey link.

### **What are my rights if I take part?**

It's totally up to you whether you take part or not. You can say yes or no at the start of the survey without upsetting people and without any impact on yourself or people you know, or the services provided to you

Information about how we will process your personal data, including your data protection rights are contained within our survey privacy notice.

You have the right to decide how much you share in each section of the survey after being presented with a summary of the section's themes being explored, including the choice not to respond.

**If you need support, guidance or any other immediate advice around your cancer or someone you have caring responsibilities for - speak directly with Young Lives vs Cancer:**

- **Telephone:** 0300 303 5220 (Monday to Friday, 09.00 to 17.00)
- **Email:** [GetSupport@younglivesvscancer.org.uk](mailto:GetSupport@younglivesvscancer.org.uk)
- **You can also access online advice via:** [www.younglivesvscancer.org.uk/contact-us/](http://www.younglivesvscancer.org.uk/contact-us/)

### **How will my 'data' or information be collected, shared or used?**

Survey data will be collecting using an online platform called Qualtrics. Data is collected and stored to be compliant with GDPR and will only be accessible to the research team at Dartington Service Design Lab and research staff at Young Lives vs Cancer, who have a data sharing agreement.

The storage and analysis of data for the purposes of the research will then be used to produce a public facing report and reports for the charities who support children & young people with cancer to help them improve services and determine future strategy.

### **What will the purpose be for processing my data / information?**

- For the recruitment of individuals to participate in the research.

- The administration of the survey.
- Collecting information from participants in accordance with the research objectives and methods.

Thank you for considering taking part in this project, we value your time and effort in responding and the insights you can offer.

As we are aiming to reach a broad range of those affected by cancer across the UK, we would be grateful if you were able to share the survey with others who may fit the recruitment criteria. This may be others within your own household, or those within a wider community or network you are already part of.

If you choose to take part in the research, please access the survey using the link below:

- [bit.ly/cancer-needs-survey](https://bit.ly/cancer-needs-survey)
- This link will be available from 20th September 2023. Data from the survey will be kept for six years after the survey closes.