

Privacy Notice - UK Survey about the impact of children and young people's cancer

The survey that you will complete has information about you. Information about you is also called your **personal data**. Personal data means any information that relates to you, or is about you. It could be your name or information about your experiences, your health or your views.

When we hold information about you, we will make sure that we keep it safe, use it fairly and that we stick to the data protection rules in the UK General Data Protection Regulation (UK GDPR) and Data Protection Act 2018.

First, though, we have some important information to tell you about how we will use your information. If you have any questions, any concerns, need to have a chat or need this information explained to you in another way, please let us know.

What?

We will only hold the information that you give to us in the survey. We won't know who you are directly from your answers. But as we may already know each other, it might be possible for us to take a guess about who you are. **We won't do this**, but it's important that we tell you that this is possible.

Why?

We are doing research into important issues to help inform our work going forward so that we can focus on key areas to help improve the lives of those affected by cancer.

The law says that we need to have a basis for holding your information, this is known as the 'lawful basis for processing'. Our lawful basis for holding your information called '**legitimate interest**'. This means that we need to use your information for our survey, which is important to us, and we have carefully thought about taken responsibility for looking after your important interests.

Some of the information is about your **health, racial or ethnic origin, religious beliefs or sexual orientation**. Information about your health is important and needs special protection. We also need to have a good reason to hold this information. **Our reason for this is that it is necessary for our research**.

You do not have to give us any information. If we couldn't process it, we would be unable to do our research.

How?

We will only hold the information that you give us. So, we will only collect information that you are comfortable with sharing with us. The information will be collected through the survey questions.

When?

We will only hold your information for as long as we need to for our survey. It will be held for six years after the close of the survey.

Who?

We are working with a research organisation called **Dartington Service Design Lab** who are helping us with this research.

Dartington Service Design Lab will see the answers that you have given to the questions. But as they don't know anything more about you, they will not know who you are, or be able to know who you are.

We use other organisations who provide us services such as email and data storage who may hold data on our behalf. They will not access or use your information.

We will not share your information with anyone else without your permission

Rights

The law gives you rights when we hold your information, and we will help you with them. Your rights are:

- To be told about why and how we are holding your information.
- To have a copy of the information we hold about you.
- To have the information fixed if it is wrong.
- To have the information deleted.
- To ask us not to use your information in a certain way.
- To ask us to stop using your information.
- To have your information transferred easily.

These rights aren't always available and can be restricted in some circumstances. If this is the case, we will only do so when we need and when it is within the data protection rules. We will let you know if this needs to happen and the reasons why.

Who to contact

If you have any questions or concerns about this survey or how we hold your personal data, you can contact:

- Our Research Team at: research@younglivesvscancer.org.uk
- Our Data Protection Team at dataprotection@younglivesvscancer.org.uk

We are regulated by the Information Commissioner (ICO) when we hold your personal data. They have helpful advice about data protection and your rights on their website: www.ico.org.uk

You have the right to make a complaint to the ICO at any time if you think that we have not handled your information in line with the rules. You can contact the ICO:

- On their website: www.ico.org.uk
- In writing: ICO, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF
- By email: icocasework@ico.org.uk