Research at Young Lives vs Cancer

Privacy Information

Hi there!

We're Young Lives vs Cancer. We help children and young people with cancer and their loved ones navigate the emotional and practical impact of cancer. We stop at nothing to make their voices heard and their unique needs understood, so they can get the right care and support at the right time.

This privacy information applies to children and young people who take part in our research, as well as parents, guardians, family members, other loved ones and professionals who may contribute to our research activities.

When we use your information, we are the **data controller** for it. This document explains how we use your **personal information** (known as **personal data**) when you take part in research, or we use your personal data for research activities.

If anything is confusing or you don't understand, you can always ask us to explain it to you.

Personal information or data is any information about you or that can identify you. It includes things like your name, contact details, reference numbers or even health information.

A Data Controller decides how and why your information is used for the research. They are responsible for complying with the law and keeping your information safe.

The Legal Bit

When we use your personal data, we need to follow data protection laws, including the UK General Data Protection Regulation (UK GDPR). This means that we must use your information fairly, keep it safe and only use it when we have a good legal reason.

Generally, our legal reason for using your personal data is called **legitimate interests**. Our legitimate interest is to conduct research into issues that affect children and young people with cancer and their families.

There may also be times when we ask for your, or your parent's or guardian's consent to use your personal data. When this is the case, we will let you know.

Legitimate Interest means that we have a good reason to use your information, but only if we have checked that it is fair, will not harm you and does not put your rights at risk.

Information such as your health is sensitive and has special protections under data protection law. We will process this type of personal data about you when:

- We have your explicit consent, or your parent's or guardian's **explicit consent**.
- It is necessary for **archiving, research or statistics**.
- It is necessary for **reasons of substantial public interest**, such as safeguarding children.

Types of personal data we use

The personal data we collect and use about you will vary depending on the type and purpose of our research. However, it will often include information about:

- Your name
- Contact details (email, address, phone number)
- Information about your health and treatment, such as diagnosis, treatment plans and wellbeing
- Demographic information (gender, racial or ethnic origin, religious or philosophical beliefs, sexual orientation, sex life)
- Economic, social or family information (such as employment, education, financial situation, social and family life).

What we do

Research is an important part of our charity's work. It helps us understand the experiences and needs of children and young people with cancer and their loved ones, so we can improve support and influence positive change.

Not all research is direct or involves active participation. Sometimes we use data and information that we already have.

Our research generally includes things like:

Surveys

Asking people a set of questions to answer

Focus Groups

Exploring issues with a small group of people discussing a topic

Interviews

A one-to-one conversation

Data Analysis

Looking at information to understand what it tells us

How long we keep your information

We can only keep your information for as long as we need it for our research purposes. This might be different in different situations. Then we will destroy or **anonymise** it.

Anonymisation means removing details that could identify you so that nobody can tell the information is about you. We might do this by removing your information or by combining it with a larger group of people.

You can ask us about how long we retain your personal data at any time.

Collecting and Sharing your Information

Most of the time, we will collect information directly from you when you give it to us, or when your parents, guardians or other loved ones give it to us. As part of our research, we may use information about you from other trusted sources. For example, we might use data from the NHS or partner organisations.

Sometimes, we use data processors to help us do our job, such as providing email services or storing information. Examples include Microsoft and our survey providers.

Sometimes we partner with other organisations or charities. They help us with our research and make it better. If we do, we'll always make sure they follow the same rules as we do to keep your information safe.

We will normally report research findings in a way that does not identify you. We do not publish names or details that could identify individual people unless we have clearly explained this to you and have permission where needed.

We might need to share your information with other individuals when we have worries about your safety or wellbeing. We will only do this when it is really needed to help keep you safe.

Your Rights

The good news is that you have control over your information, and the law gives you rights that you can use at any time.

You have the right to ask us to:

- Show you your information
- Send it to someone else
- Stop using it in a certain way
- Pause how we use it
- Delete it
- Fix any mistakes

Not all of these rights apply all the time. If we can't do something you have asked us to do, we will tell you and explain why.

Don’t worry, we will always help you to use these rights. You just need to ask or contact dataprotection@younglivesvscancer.org.uk and we’ll be able to give you more information.

Our promise to you

When we use your information for research, we know that you are putting a lot of trust in us to keep it safe and secure. We take this very seriously. So, when you give us your information and we use it for research, we promise that:

1. We will respect your choice about taking part in research and your choice to change your mind.
2. We will be open about how we use your information and only use it for the reasons we have told you about.
3. We will only collect and use what we need.
4. We will protect it and keep it secure.
5. We will not share it with any other person or organisation without your say-so, unless we are allowed or required to do so by law.
6. We will always follow the law.
7. We will carefully think about any risks that using the information may cause you and make sure we put things in place to reduce those risks.
8. We will never use the information to make specific decisions about you or in ways that would cause you harm.
9. We will only keep it for as long as we need it, then either delete it or anonymise it.
10. We will always carry out our research in an ethical and responsible way.

Get in touch!

If you have any questions about this document, how we use your information, or how to use your rights, just ask! You can also contact us at **dataprotection@younglivesvscancer.org.uk**.

If you think we haven't lived up to our promises or you are worried we may have broken the law, you have the right to make a complaint to us at any time. Making a complaint will not affect any support you receive from us.

You can also speak to, or make a complaint to, the Information Commissioner's Office, which keeps us in check, if you think we haven't followed the rules. Their website is **www.ico.org.uk** and their phone number is **0303 123 1113**.

Don't worry, we're always on hand to answer any questions or worries you might have about this document or your personal information.

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