



Default Question Block

Children's Cancer Priority Setting Partnership Survey for Young People

We are looking for questions about children's cancer.

We are asking children and young people who have experienced cancer, their families and friends to tell us what questions they would like research to answer. 'Research' is what we do when we want to learn more about something or find out something new. By telling us what you think, we can help make sure that research answers questions that are important to people like you.

We want to know what matters to you.

We want to know what you think is important for us to find out about having cancer, or having a brother, sister or friend who has cancer. You are the expert on this so what you think is really important.

Who can take part?

This survey is for:

- Young people who have been diagnosed with cancer before they were 16 years old. You can take part if you have cancer now or had cancer when you were younger.
- Young people who have a brother, sister or friend with cancer now or who had cancer when they were younger.

What do I need to do?

We would like you to tell us what matters to you. You can write this in our form on a phone, tablet or computer. If you need help, you can ask someone to help you. You can write down questions you would like to know the answer to. If it's hard to write what is important to you as a question, you can just write it in your own words.

Who will know what I tell you?

We will make sure that nobody can tell which things you told us. We will not ask for your name. We will ask for a few details about you, like how old you are. This is to make sure we include ideas from lots of different people. You don't have to tell us any of the things we ask about you.

What will happen to what I tell you?

Each question will be checked to see if we already know enough about it. If we don't know enough about it, we will add it to a list. We will then ask children and young people which questions on the list are most important. We will also ask families and people who look after children and young people, like doctors and nurses, which questions they think are most important. At the end of this project, we

will have a list of the 10 questions that are most important to children, young people, families and the people who look after them. We will put all the questions on the James Lind Alliance website <http://www.jla.nihr.ac.uk/top-10-priorities/>. We will tell people who do research and fund research about the questions so they know what is important.

Who is doing this project?

This project is called the 'Children's Cancer Priority Setting Partnership'. You can read more about it and see who is involved here: <https://www.cclg.org.uk/Childrens-Cancer-PSP>. It is organised by the Children's Cancer and Leukaemia Group (CCLG) and Little Princess Trust, which are charities that work with children who have cancer and their families.

If you want to get in touch with us please email ChildCancerPSP@surrey.ac.uk or ask your parent/carer to email us.

About you

About you

We would like you to tell us a few things about you so we can make sure everyone's ideas are included. If you don't want to tell us any of these things you don't have to. You can ask someone for help if you need it.

Who are you?

- Someone who has been diagnosed with cancer
- Brother or sister of someone who has been diagnosed with cancer
- Friend of someone who has been diagnosed with cancer

What best describes your gender?

- Male
- Female
- use another word. Please write this in:
- I prefer not to answer this

How old are you?

- Please write in how old you are:
- I prefer not to answer this

Which country do you live in?

- England
- Scotland
- Wales
- Northern Ireland
- Somewhere else - please write in:
- I prefer not to answer this

What is your ethnic group?

- White
- Mixed/multiple ethnic groups
- Asian or Asian British
- Black African, Black Caribbean or Black British
- Other - please write in:
- I prefer not to answer this

Questions for young people with cancer

Which cancer were you diagnosed with?

- Bone tumour
- Brain or spinal tumour
- Germ cell tumour
- Kidney tumour
- Langerhans Cell Histiocytosis (LCH)
- Leukaemia
- Liver tumour
- Lymphoma
- Neuroblastoma
- Retinoblastoma
- Soft tissue sarcoma
- I am not sure - please write in cancer type
- Other - please write in cancer type

I prefer not to answer this

How old were you when you were diagnosed with cancer?

- Please write in your age at diagnosis in years:
- I was under one year old
- I am not sure
- I prefer not to answer this

Which of the following best describes your current situation?

- Not yet given a diagnosis
- On treatment
- Finished treatment in the last 0 to 12 months
- Finished treatment 1 to 5 years ago
- Finished treatment more than 5 years ago
- I am not sure
- Other - please write in:
- I prefer not to answer this

Questions for siblings and friends

Which cancer was your brother/ sister/ friend diagnosed with?

- Bone tumour
- Brain or spinal tumour
- Germ cell tumour
- Kidney tumour
- Langerhans Cell Histiocytosis (LCH)
- Leukaemia
- Liver tumour
- Lymphoma
- Neuroblastoma
- Retinoblastoma
- Soft tissue sarcoma

- I am not sure - please write in cancer type
- Other - please write in cancer type
- I prefer not to answer this

How old was your brother/ sister/ friend when they were diagnosed with cancer?

- Please write in their age at diagnosis in years:
- They were under one year old
- I am not sure
- I prefer not to answer this

Which of the following best describes your brother/ sister/ friend's situation?

- Not yet given a diagnosis
- On treatment
- Finished treatment in the last 0 to 12 months
- Finished treatment 1 to 5 years ago
- Finished treatment more than 5 years ago
- Passed away
- I am not sure
- Other - please write in:
- I prefer not to answer this

Your questions

Your questions

From your experience of having cancer or knowing someone with cancer, we want to know what questions you would like answered.

It's up to you what you want to write about. Some things you might want to think about are:

Going to or visiting hospital

Having treatment

Going to school

Talking with friends about cancer

Side effects of cancer treatment

How well treatment works

How you feel

How people look after you

Or anything else that matters to you.

You can write as many things as you want. We are interested in what matters to you so there are no right or wrong answers. If there is something that really matters to you but you can't think how to write it as a question, please still tell us in your own words.

Please write the first thing that matters to you here

Please write the next thing that matters to you here

Please write the next thing that matters to you here

Would you like to write another thing that matters to you?

- Yes
- No

It's up to you what you want to write about. Some things you might want to think about are:

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Talking with friends about cancer

Side effects of cancer treatment

How well treatment works

How you feel

How people look after you

Or anything else that matters to you.

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Or anything else that matters to you.

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Final page

You have finished.

Please press the 'Submit' button to send us your survey.

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