introduction

Children’s Cancer Priority Setting Partnership Survey

We are looking for questions to help guide research about children’s cancer

We are asking all those directly affected by, or involved with, childhood cancer* to tell us what questions they would like research to focus on answering. The questions will be made available to research funders to ensure that they are aware of what matters most to children, their families and friends, and professionals and that their views are at the heart of future research.

Who do we want to hear from?

We would like to invite you to complete this survey if you are aged 16 years or over and:

- You have cancer now, or you have had cancer in the past, and you were diagnosed before your 16th birthday (it does not matter what age you are now).
- You are a relative/friend/partner/carer of someone who has been diagnosed with cancer under the age of 16 years.
- You are a professional involved in diagnosing or treating children who have cancer or had cancer under the age of 16 years.
- You are a professional involved in the care of children who have cancer or had cancer under the age of 16 years and/or their families.

We also want to hear from children and young people who are under 16 years old. Children and young people’s versions of the survey will be available later in the year. You can tell us at the end of survey if you would like us to let you know when they are available. If you are under 16 and don’t want to wait until the other versions of the survey are available, please go ahead and fill in this survey.

The survey should take around 20 minutes to complete. For your response to be submitted you need to select the 'Submit' button at the end of the survey.

What will happen to my question(s)?

Each question or topic will be checked to see if it has already been answered by existing research. Questions that have not been answered will be put in order of importance. This will be done by patients, carers and professionals through a follow-up survey and a workshop. If you are interested in taking part, you can tell us at the end of this survey.
By participating in this survey you give us, and partner organisations (https://www.cclg.org.uk/Childrens-Cancer-PSP/Partners), permission to publish your questions for the Priority Setting Partnership, but the information you give will be anonymised (you will not be identifiable from what you have told us). If you provide contact details, your name will not be published in association with your question(s). For more information, or to see what published questions look like, please go to http://www.jla.nihr.ac.uk/top-10-priorities/.

Who is involved in this project?

This survey is being overseen by the Children’s Cancer Priority Setting Partnership (PSP) Steering Group; led by the James Lind Alliance in partnership with the Children’s Cancer and Leukaemia Group (CCLG) and Little Princess Trust. You can find more information about the Children’s Cancer PSP and this survey here https://www.cclg.org.uk/Childrens-Cancer-PSP by emailing ChildCancerPSP@surrey.ac.uk or by telephoning 01483 684132 (Susie Aldiss, Researcher).

For further information about the James Lind Alliance please go to http://www.jla.nihr.ac.uk/.

* Including cancer-like conditions such as benign brain tumours

About you

Information about you

We would like to know about who is answering this survey so we can make sure that we include questions from a wide range of people with different experiences of childhood cancer.

Who are you?

○ Someone who was diagnosed with cancer as a child (before their 16th birthday)
○ Parent/carer of someone who was diagnosed with cancer as a child
○ Relative of someone who was diagnosed with cancer as a child
○ Friend of someone who was diagnosed with cancer as a child
○ Partner of someone who was diagnosed with cancer as a child
○ Professional working with children who have cancer/had cancer and/or their families

To answer the survey you can only select one choice from this list. If you are someone who falls into more than one of these categories (for example you are a professional who had cancer as a child) please select the one that feels most relevant for you or the one that represents the perspective you wish to answer the survey from. If you would like to tell us that you could have selected more than one choice you can do so in the comments box towards the end of survey.

Questions for professionals

What is your profession?

○ Doctor
○ Nurse
○ ______ Allied Health Professional - please specify
○ ______ Social Care Professional - please specify
○ ______ Educational Professional - please specify
○ ______ Other - please specify

Please specify - do you mostly work in:

○ Primary care
○ Secondary care
○ Tertiary care
○ ______ Other - please specify

Are you a:

○ Children's Cancer Nurse

○ Children's Nurse
○ Children's Community Nurse
○ ▭ Other - please specify

Questions for families/friends/partners/carers

Which cancer was your child/relative/friend/partner 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
☐ ▭ Not sure, please write in cancer type
☐ ▭ Other - please write in cancer type
☐ Prefer not to answer

How old was your child/relative/friend/partner when they were diagnosed with cancer?

○ ▭ Please write in their age at diagnosis in years
○ They were under one year old
○ Not sure
○ Prefer not to answer

Which of the following best describes your child/relative/friend/partner’s current situation?

You can select more than one response if you wish.

☐ Not yet given a diagnosis
☐ On treatment
☐ On treatment for relapse
☐ Finished treatment in the last 0 to 12 months
☐ Finished treatment 1 to 5 years ago
☐ Finished treatment more than 5 years ago
☐ Receiving palliative care
☐ Passed away
☐ Not sure
☐ ▭ Other - please write in

☐ Prefer not to answer

Questions for patients/survivors

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
☐ ______ Not sure - please write in cancer type
☐ ______ Other - please write in cancer type
☐ Prefer not to answer

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
○ Not sure
○ Prefer not to answer

Which of the following best describes your current situation?

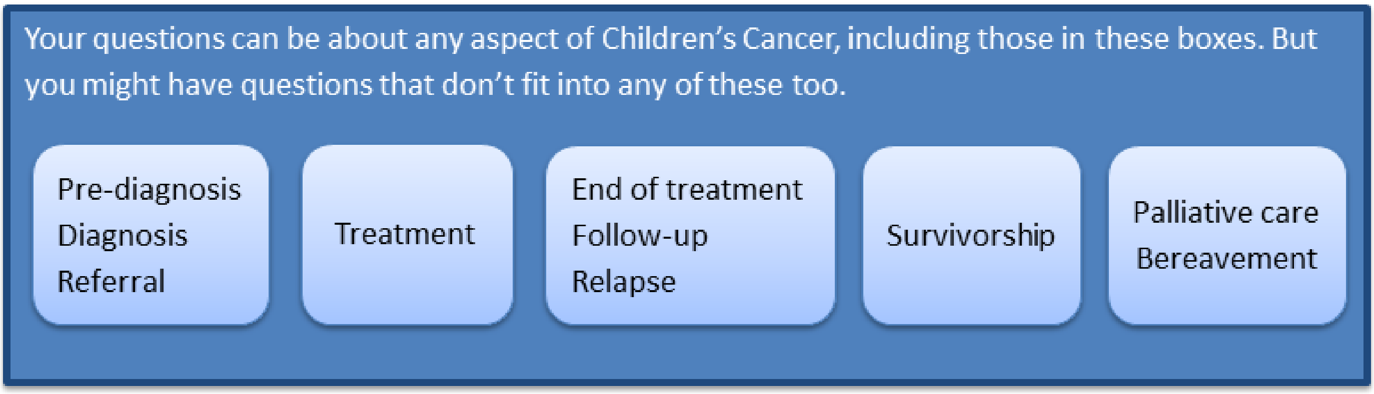
You can select more than one response if you wish.

☐ Not yet given a diagnosis
☐ On treatment
☐ On treatment for relapse
☐ Finished treatment in the last 0 to 12 months
☐ Finished treatment 1 to 5 years ago
☐ Finished treatment more than 5 years ago
☐ Receiving palliative care
☐ Not sure
☐ ______ Other - please write in
☐ Prefer not to answer

research questions

Your questions

Your experience and knowledge, as someone who has been directly affected by childhood cancer, is essential in helping us identify the most important questions that need to be researched. We want to know what matters most to you. If you can't think how to write what matters to you as a question please still tell us in your own words.



Your questions can be about any aspect of Children's Cancer, including those in these boxes. But you might have questions that don't fit into any of these too.

- Pre-diagnosis
Diagnosis
Referral
- Treatment
- End of treatment
Follow-up
Relapse
- Survivorship
- Palliative care
Bereavement

When thinking about possible questions some things you could think about are:

- Improving treatment and care
- Communication
- Short or long-term side effects
- Emotional well-being
- Family, relationships and social life
- Late impact of treatment
- Education
- Delivery of services for children with cancer and their families/carers

Your questions could also be about anything else not in these categories.

What should research focus on?

You can write as many questions as you want. They can be written in any order of importance. **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 your first question here:

What is your next question? (Please leave blank if you do not have any further questions)

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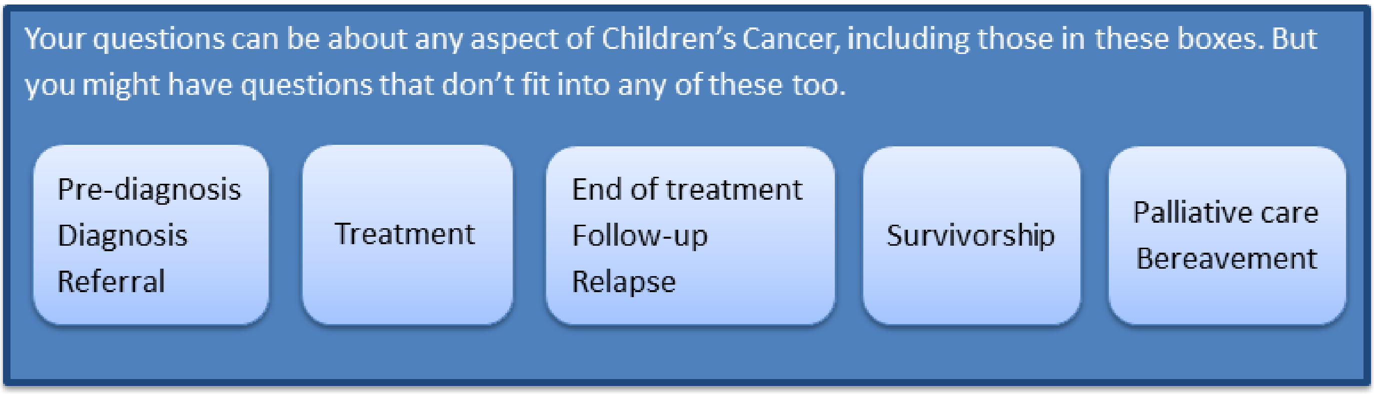
Do you have another question you would like to add?

○ Yes

○ No



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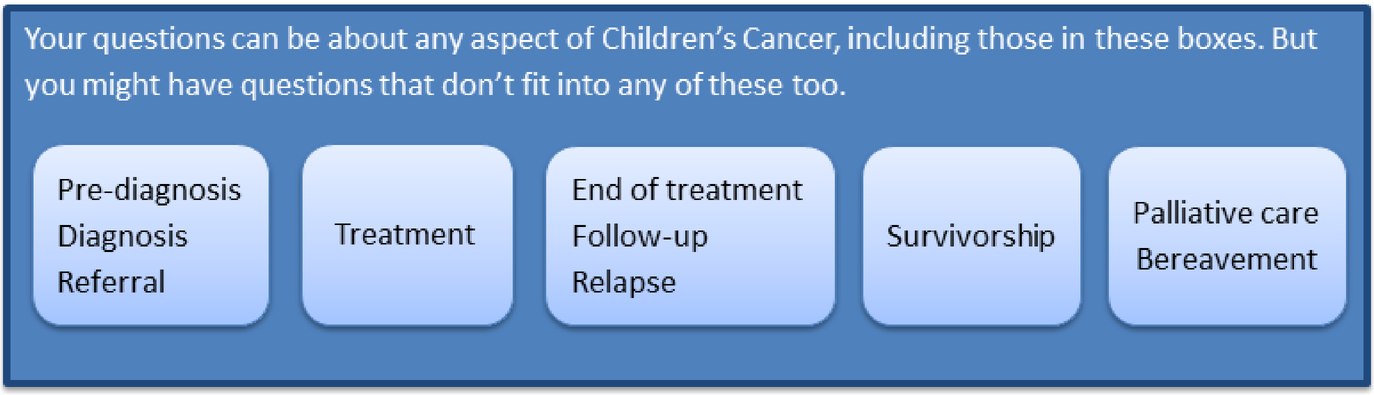
What is your next question?

Do you have another question you would like to add?

○ Yes

○ No



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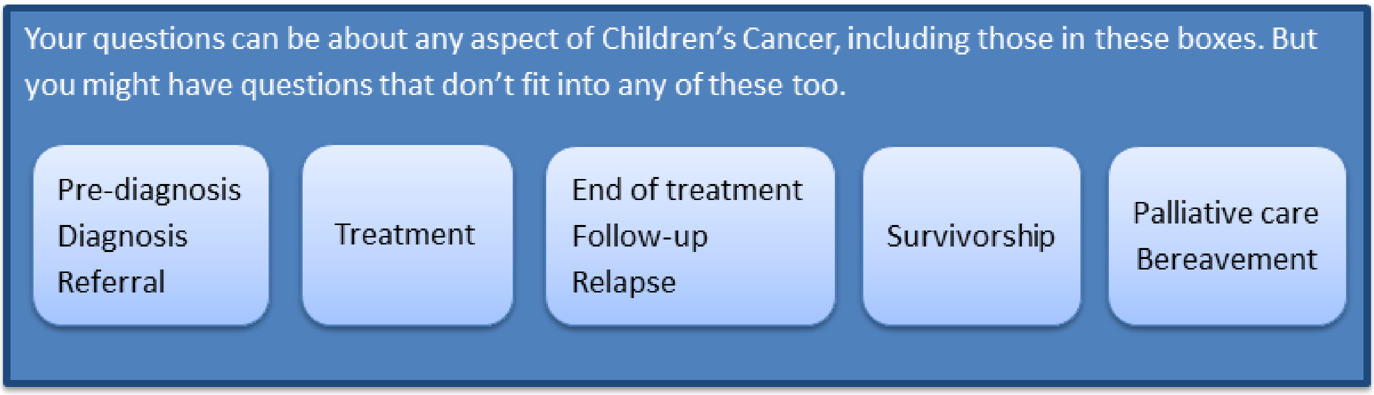

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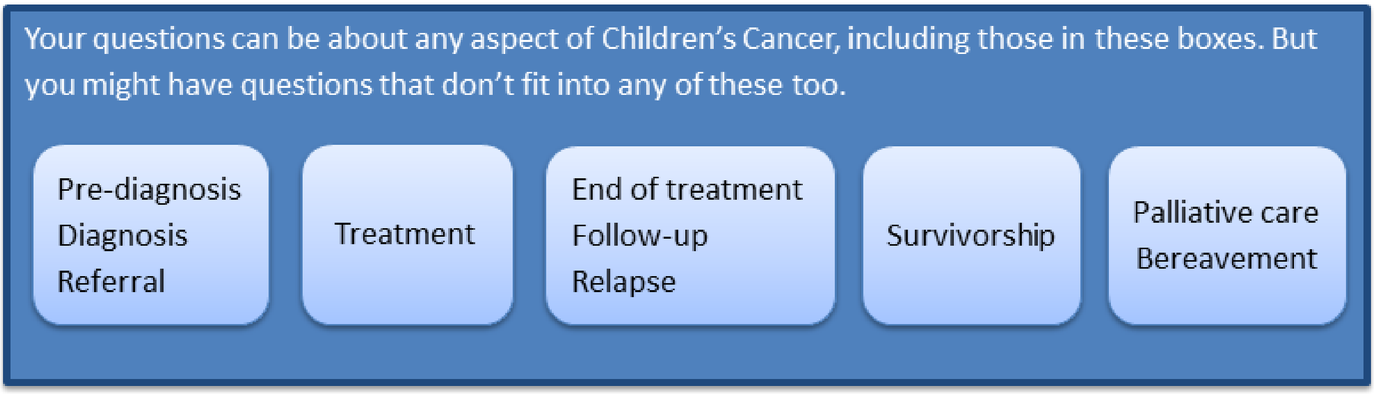

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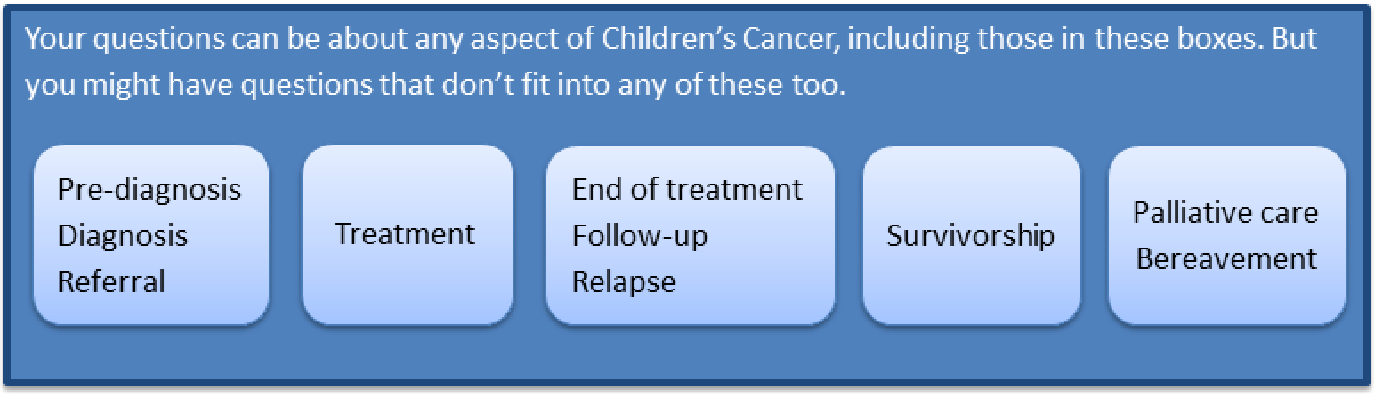
Do you have another question you would like to add?

○ Yes

○ No



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Improving treatment and care

Communication

Short or long-term side effects

Emotional well-being

Family, relationships and social life

Late impact of treatment

Education

Delivery of services for children with cancer and their families/carers

Your questions could also be about anything else not in these categories.

What is your next question?

Do you have any additional comments you would like to share with us?

More information about you

More information about you

We would like to know a bit more about you, again this is so we can make sure we include ideas from people with different experiences of childhood cancer.

What best describes your gender?

○ Male
○ Female
○ I use another term (for example, non-binary) - please write in:
○ Prefer not to answer

Do you consider yourself to be trans?

Trans is an umbrella term to describe people whose gender is not the same as, or does not sit comfortably with, the sex they were assigned at birth.

○ Yes
○ No
○ Prefer not to answer

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
○ Prefer not to answer

How old are you?

○ Under 16 - please write in how old you are
○ 16-18
○ 19-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64

○ 65+

○ Prefer not to answer

Please select the country you live in:

○ England

○ Scotland

○ Wales

○ Northern Ireland

○ ________________ Other - please write in

○ Prefer not to answer

How old are you?

○ 16-18

○ 19-24

○ 25-34

○ 35-44

○ 45-54

○ 55-64

○ 65+

○ Prefer not to answer

Please select the country you work in:

○ England

○ Scotland

○ Wales

○ Northern Ireland

○ ________________ Other - please write in

○ Prefer not to answer

Block 6

Next steps

Would you like to be involved in the next stage of the project, which is to vote for the questions you think are most important of all those submitted?

This would involve taking part in another online survey.

○ Yes

○ No

Would you like to be notified when the surveys for children and young people under 16 are available?

These surveys will be for children and young people who have been diagnosed with cancer, their siblings and friends.

○ Yes

○ No

Please enter your name and email address and we will be in touch

Name	
Email	

If you are under 16 years old, please ask a parent/carer to email us - ChildCancerPSP@surrey.ac.uk with your contact details

All contact details will be kept confidential and secure, in accordance with General Data Protection Regulation (GDPR). We will not publish your details and they will not be linked to your responses on this survey. We will not use your details for any purpose other than inviting you to take part in the next stage or letting you know about the surveys for children and young people.