

Have your say about childhood cancer research.

Who are we?

We are a group of people who have had childhood cancer, are family members of a child with cancer and healthcare professionals taking care of children with cancer, and we are conducting a priority-setting partnership in Canada to understand the needs and priorities of others impacted by cancer.

We're asking:

Children and teens with cancer, Survivors of childhood cancer, Family members of children and teens who have (or had) cancer, and Healthcare professionals who care for children and teens with cancer or survivors To help us identify the top 10 unanswered questions they want cancer researchers to answer. This will help to guide cancer and survivorship research in a way that is led by the people childhood cancer affects the most.

What will I need?

To complete this survey, you will need a reliable internet connection. The survey should take 5-10 minutes to complete.

Frequently Asked Questions

What do we mean by unanswered questions? We're looking for questions about any part of the childhood cancer path, from diagnosis to treatment to relapse to survivorship to palliative/end-of-life care.

These questions can be about cancer cells, drugs, friends, family, government and healthcare policies, or anything else you think is important to know about.

"How can I maintain my child's mental health while they receive cancer treatment?" "Which cancer treatments are available to me?" "How can I feel supported in managing my cancer at school or during my daily activities?" "What will we do with the results? We will share the results of this survey with researchers, healthcare professionals, patients, survivors, family members, and research funders to guide future childhood cancer research in Canada.

What will happen to my information? Questions you enter in the survey will be shared but not linked to you personally in any way. Any information that could identify you will remain confidential.

Want to know more about the study?

Check out our website, email your questions to lindsay.jibb@sickkids.ca, or contact us via social media (info below). If you have any questions about your rights as a research participant, you may contact the Office of the Research Ethics Board at 416-813-8279 during business hours.

Other information: You will not be paid for being in this study. This survey involves minimal risk to you. The benefits, however, may impact society by helping increase knowledge about children's cancer. You do not have to be in this study if you do not want to be. You do not have to answer any questions that you do not want to answer for any reason.

Connect with us

Twitter: [PedCancerPSP](#) Instagram: [pedcancerpsp](#) LinkedIn Group: [Pediatric Cancer Priority Setting Partnership](#) Facebook Group: [Pediatric Cancer Priority Setting Partnership](#)

Have a look at this video to learn more about who we are and what this project is all about!

Survey By completing this survey you are consenting to its use in research.

Once you have submitted your responses for this anonymous survey, your answers will be put into a database and will not be identifiable to you This means that once you have submitted your survey, your responses cannot be withdrawn from the study.

Which of the following best describes you?

- I am a child or teen with cancer or a survivor of childhood cancer
- I am a family member or friend of a child with cancer or survivor
- I am a family member or friend of a child with cancer or survivor completing this survey on the child's behalf
- I am a healthcare professional who takes care of children with cancer or survivors
- None of the above

Thank you for your interest in our survey! At this time, we are looking for feedback from the groups listed above, but encourage you to continue participating in similar surveys in the future.

Do you identify as:

- Female
- Male
- Prefer not to say
- Prefer to self-describe

Do you identify as:

- Female
- Male
- Prefer not to say
- Prefer to self-describe

Do you identify as:

- Female
- Male
- Prefer not to say
- Prefer to self-describe

Do you identify as:

- Female
- Male
- Prefer not to say
- Prefer to self-describe

Please describe:

Please describe:

Please describe:

Please describe:

What is your age (in years)?

(Please use numbers ranging from 0-100)

What is your age?

(Please use numbers ranging from 0-100)

The child is:

- Less than one year old
 One year old or older
-

What is the child's age (in years)?

(Please use numbers ranging from 0-100)

What is your age?

(Please use numbers ranging from 1-100)

Racial/ Ethnic group

- Arab, Middle Eastern or West Asian (examples: Afghan, Armenian, Iranian, Lebanese, Persian, Turkish)
 Black (examples: African, African-Canadian, Afro-Caribbean)
 East Asian (examples: Chinese, Japanese, Korean)
 First Nations (status, non-status, treaty or non-treaty), Inuit or Métis
 Latin American (examples: Brazilian, Colombian, Cuban, Mexican, Peruvian)
 South Asian or Indo-Caribbean (examples: Indian, Indo-Guyanese, Indo-Trinidadian, Pakistani, Sri Lankan)
 Southeast Asian (examples: Filipino, Malaysian, Singaporean, Thai, Vietnamese)
 White (examples: English, Greek, Italian, Portuguese, Russian, Slovakian)
 More than one race category
 Not listed
 Prefer not to answer
-

Please select all that apply

- Arab, Middle Eastern or West Asian
 Black
 East Asian
 First Nations, Inuit or Métis
 Latin American
 South Asian or Indo-Caribbean
 Southeast Asian
 White
 Not listed
-

Please describe

Racial/ Ethnic group

- Arab, Middle Eastern or West Asian (examples: Afghan, Armenian, Iranian, Lebanese, Persian, Turkish)
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- Southeast Asian (examples: Filipino, Malaysian, Singaporean, Thai, Vietnamese)
- White (examples: English, Greek, Italian, Portuguese, Russian, Slovakian)
- More than one race category
- Not listed
- Prefer not to answer

Please select all that apply

- Arab, Middle Eastern or West Asian
- Black
- East Asian
- First Nations, Inuit or Métis
- Latin American
- South Asian or Indo-Caribbean
- Southeast Asian
- White
- Not listed

Please describe

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- More than one race category
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- Prefer not to answer

Please select all that apply

- Arab, Middle Eastern or West Asian
- Black
- East Asian
- First Nations, Inuit or Métis
- Latin American
- South Asian or Indo-Caribbean
- Southeast Asian
- White
- Not listed

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- More than one race category
- Not listed
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Please select all that apply

- Arab, Middle Eastern or West Asian
- Black
- East Asian
- First Nations, Inuit or Métis
- Latin American
- South Asian or Indo-Caribbean
- Southeast Asian
- White
- Not listed

Please describe

Please specify:

Please specify:

Please specify:

Please specify:

What Canadian province/territory are you from? If you are not from Canada, please enter the name of the country you are from.

- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon
- Other country (please specify)

What Canadian province/territory are you from? If you are not from Canada, please enter the name of the country you are from.

- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia
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- Ontario
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- Saskatchewan
- Yukon
- Other country (please specify)

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- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon
- Other country (please specify)

Please specify

Please specify

Please specify

Please specify

How far away do you live from your nearest primary cancer care centre?

- More than 100 km
 Less than or equal to 100 km
 Not sure
-

How far away do you live from your nearest primary cancer care centre?

- More than 100 km
 Less than or equal to 100 km
 Not sure
-

How far away do you live from your nearest primary cancer care centre?

- More than 100 km
 Less than or equal to 100 km
 Not sure
-

How far away do you live from your nearest primary cancer care centre?

- More than 100 km
 Less than or equal to 100 km
 Not sure
-

What type of cancer were you first diagnosed with?

- Leukemia
 Lymphoma
 Brain or spinal cord cancer
 Neuroblastoma
 Retinoblastoma
 Kidney cancer
 Liver cancer
 Bone cancer
 Soft tissue cancer
 Germ cell and gonad cancer
 Skin cancer
 Thyroid cancer
 Other (please specify)
-

What type of relationship do you have with the child or survivor?

- Father
 Mother
 Friend
 Spouse/partner
 Other
-

What type of cancer was the child or survivor first diagnosed with?

- Leukemia
 Lymphoma
 Brain or spinal cord cancer
 Neuroblastoma
 Retinoblastoma
 Kidney cancer
 Liver cancer
 Bone cancer
 Soft tissue cancer
 Germ cell and gonad cancer
 Skin cancer
 Thyroid cancer
 Other (please specify)

What type of cancer was the child or survivor first diagnosed with?

- Leukemia
- Lymphoma
- Brain or spinal cord cancer
- Neuroblastoma
- Retinoblastoma
- Kidney cancer
- Liver cancer
- Bone cancer
- Soft tissue cancer
- Germ cell and gonad cancer
- Skin cancer
- Thyroid cancer
- Other (please specify)

Please specify

- B-cell ALL (acute lymphoblastic leukemia)
- T-cell ALL (acute lymphoblastic leukemia)
- Acute myeloid leukemia
- Other leukemia
- I don't know

Please specify

- B-cell ALL (acute lymphoblastic leukemia)
- T-cell ALL (acute lymphoblastic leukemia)
- Acute myeloid leukemia
- Other leukemia
- I don't know

Please specify

- B-cell ALL (acute lymphoblastic leukemia)
- T-cell ALL (acute lymphoblastic leukemia)
- Acute myeloid leukemia
- Other leukemia
- I don't know

Please describe

Please describe

Please describe

Please specify

- Hodgkin lymphoma
- Non-Hodgkin lymphoma
- Burkitt lymphoma
- Other lymphoma
- I don't know

Please specify

- Hodgkin lymphoma
- Non-Hodgkin lymphoma
- Burkitt lymphoma
- Other lymphoma
- I don't know

Please specify

- Hodgkin lymphoma
- Non-Hodgkin lymphoma
- Burkitt lymphoma
- Other lymphoma
- I don't know

Please describe

Please describe

Please describe

Please specify

- Ependymoma
- High grade glioma/glioblastoma
- Low grade glioma
- Medulloblastoma
- ATRT (atypical teratoid rhabdoid tumour)
- PNET (primitive neuroectodermal tumor)
- Choroid plexus papilloma
- Choroid plexus carcinoma
- Other brain or spinal cord cancer
- I don't know

Please specify

- Ependymoma
- High grade glioma/glioblastoma
- Low grade glioma
- Medulloblastoma
- ATRT (atypical teratoid rhabdoid tumour)
- PNET (primitive neuroectodermal tumor)
- Choroid plexus papilloma
- Choroid plexus carcinoma
- Other brain or spinal cord cancer
- I don't know

Please specify

- Ependymoma
- High grade glioma/glioblastoma
- Low grade glioma
- Medulloblastoma
- ATRT (atypical teratoid rhabdoid tumour)
- PNET (primitive neuroectodermal tumor)
- Choroid plexus papilloma
- Choroid plexus carcinoma
- Other brain or spinal cord cancer
- I don't know

Please describe

Please describe

Please describe

Please specify

- Nephroblastoma
- Other kidney cancer
- I don't know

Please specify

- Nephroblastoma
- Other kidney cancer
- I don't know

Please specify

- Nephroblastoma
- Other kidney cancer
- I don't know

Please describe

Please describe

Please describe

Please specify

- Hepatoblastoma
- Other liver cancer
- I don't know

Please specify

- Hepatoblastoma
- Other liver cancer
- I don't know

Please specify

- Hepatoblastoma
- Other liver cancer
- I don't know

Please describe

Please describe

Please describe

Please specify

- Osteosarcoma
- Ewing sarcoma
- Other bone cancer
- I don't know

Please specify

- Osteosarcoma
- Ewing sarcoma
- Other bone cancer
- I don't know

Please specify

- Osteosarcoma
- Ewing sarcoma
- Other bone cancer
- I don't know

Please describe

Please describe

Please describe

Please specify

- Rhabdomyosarcoma
- Fibrosarcoma
- Other soft tissue sarcoma
- I don't know

Please specify

- Rhabdomyosarcoma
- Fibrosarcoma
- Other soft tissue sarcoma
- I don't know

Please specify

- Rhabdomyosarcoma
- Fibrosarcoma
- Other soft tissue sarcoma
- I don't know

Please describe

Please describe

Please describe

Please specify

Please specify

Please specify

Please specify

What year were you first diagnosed with cancer?

_____ ((YYYY) Please indicate a year between 1900-2020)

What year was the patient or survivor first diagnosed with cancer?

_____ ((YYYY) Please indicate a year between 1900-2020)

What year was the patient or survivor first diagnosed with cancer?

_____ ((YYYY) Please indicate a year between 1900-2020)

What best describes your current cancer experience? You can select more than one option.

- I am receiving cancer treatment right now
- I have relapsed cancer
- I am a cancer survivor
- I am receiving end-of-life care
- Other (please specify)
- Not sure

How many times did you relapse?

(Please use numbers ranging from 1-100)

What was the year of your last relapse?

((YYYY) Please indicate a year between 1900-2020)

How long (in years) have you been a survivor of childhood cancer?

(Please use numbers ranging from 1-100)

What best describes the child or survivor's current cancer experience? You can select more than 1 option

- My child is receiving cancer treatment right now
- My child has relapsed cancer
- My child is a cancer survivor
- My child is receiving end-of-life care
- My child has passed away
- Other (please specify)
- Not sure

How many times did your child relapse?

(Please use numbers ranging from 1-100)

What was the year of your child's last relapse?

((YYYY) Please indicate a year between 1900-2020)

How long (in years) has your child been a survivor of childhood cancer?

(Please use numbers ranging from 1-100)

What best describes the child or survivor's current cancer experience? You can select more than 1 option

- They are receiving cancer treatment right now
- They have relapsed cancer
- They are a cancer survivor
- They are receiving end-of-life care
- Other (please specify)
- Not sure

How many times did your child relapse?

(Please use numbers ranging from 1-100)

How long (in years) has the child been a survivor of childhood cancer?

(Please use numbers ranging from 1-100)

What was the year of the child's last relapse?

((YYYY) Please indicate a year between 1900-2020)

What is your healthcare profession?

- Oncologist
- Registered nurse
- Registered practical nurse
- Advanced practice nurse
- Physical therapist
- Occupational therapist
- Psychologist
- Speech language pathologist
- Pharmacist
- Dietician
- Child life specialist
- Social Worker
- Other (please specify)

Please specify

For how many years have you worked in pediatric oncology?

(Please include a numeric value from 1-100)

Please describe

Please describe

Please describe

Are/were you diagnosed with a cancer that is/was considered 'high-risk' (for example your cancer relapsed, did not go away even after your treatment, was metastatic or widespread, or was called high-risk for another reason)?

- Yes
- No
- I don't know

Is/was your child diagnosed with a cancer that is/was considered 'high-risk' (for example your child's cancer relapsed, did not go away even after your treatment, was metastatic or widespread, or was called high-risk for another reason)?

- Yes
- No
- I don't know

Is/was the child diagnosed with a cancer that is/was considered 'high-risk' (for example the cancer relapsed, did not go away even after your treatment, was metastatic or widespread, or was called high-risk for another reason)?

- Yes
- No
- I don't know

Have you had an experience with new cancer treatments (or 'novel therapies') that might help fight your cancer?

- Yes
- No
- I don't know

These may be drugs or other treatments that are not approved or funded in Canada for children's cancer. These drugs and treatments are sometimes available through an early phase clinical trial or special access programs.

Have you had an experience with new cancer treatments (or 'novel therapies') that might help fight your child's cancer?

- Yes
 No
 I don't know

These may be drugs or other treatments that are not approved or funded in Canada for children's cancer. These drugs and treatments are sometimes available through an early phase clinical trial or special access programs.

Has the child had an experience with new cancer treatments (or 'novel therapies') that might help fight their child's cancer?

- Yes
 No
 I don't know

These may be drugs or other treatments that are not approved or funded in Canada for children's cancer. These drugs and treatments are sometimes available through an early phase clinical trial or special access programs.

Were you able to receive these new cancer treatments (or 'novel therapies') when you needed them?

- Yes
 No
 I started the process of getting these treatments but could not continue

Was your child able to receive these new cancer treatments (or 'novel therapies') when they needed them?

- Yes
 No
 We started the process of getting these treatments but could not continue

Was the child able to receive these new cancer treatments (or 'novel therapies') when they needed them?

- Yes
 No
 I started the process of getting these treatments but could not continue

Which types of new cancer treatments (or 'novel therapies') did you receive or try to receive? You may select more than one response.

- A drug or treatment that is not approved in Canada for children or adults with cancer (it may be available through a clinical trial)
 A drug or treatment that is approved for adults with cancer but not usually used for children with cancer (it may be available through a clinical trial)
 A drug or treatment that is not funded in Canada for children with cancer
 Other
 I don't know

Which types of new cancer treatments (or 'novel therapies') did your child receive or try to receive? You may select more than one response.

- A drug or treatment that is not approved in Canada for children or adults with cancer (it may be available through a clinical trial)
 A drug or treatment that is approved for adults with cancer but not usually used for children with cancer (it may be available through a clinical trial)
 A drug or treatment that is not funded in Canada for children with cancer
 Other
 I don't know

Which types of new cancer treatments (or 'novel therapies') did the child receive or try to receive?
You may select more than one response.

- A drug or treatment that is not approved in Canada for children or adults with cancer (it may be available through a clinical trial)
- A drug or treatment that is approved for adults with cancer but not usually used for children with cancer (it may be available through a clinical trial)
- A drug or treatment that is not funded in Canada for children with cancer
- Other
- I don't know

Please describe

Please describe

Please describe

How many times did you try to receive these new cancer treatments (or 'novel therapies')?

(Please use numbers ranging from 0-100)

How many times did your child try to receive these new cancer treatments (or 'novel therapies')?

(Please use numbers ranging from 0-100)

How many times did the child try to receive these new cancer treatments (or 'novel therapies')?

(Please use numbers ranging from 0-100)

How many times did you actually receive these new cancer treatments (or 'novel therapies')?

(Please use numbers ranging from 0-100)

How many times did your child actually receive these new cancer treatments (or 'novel therapies')?

(Please use numbers ranging from 0-100)

How many times did the child actually receive these new cancer treatments (or 'novel therapies')?

(Please use numbers ranging from 0-100)

Please briefly tell us why you could or could not start or continue to use these new cancer treatments:

Please briefly tell us why your child could or could not start or continue to use these new cancer treatments:

Please briefly tell us why the child could or could not start or continue to use these new cancer treatments:

What questions (up to five) do you have about pediatric cancer and/or survivorship, their treatment or support services?

Question 1

Question 1

Question 1

Question 1

Question 2

Question 2

Question 2

Question 2

Question 3

Question 3

Question 3

Question 3

Question 4

Question 4

Question 4

Question 4

Question 5

Question 5

Question 5

Question 5

OPTIONAL: Please provide us with any feedback you may have about the survey

Thank you for participating!

If you would like to hear about other projects we are doing related to this work, or stay informed about this project, please provide your contact information by completing this form [insert hyperlink].

If you have any questions or comments about the survey you completed or the Pediatric Cancer Priority Setting Partnership, please reach out to Lindsay Jibb at lindsay.jibb@sickkids.ca.