

# Under 16 Cancer Patient Experience Survey PARENT / CARER SURVEY

We want to hear about your experiences of receiving care and treatment for your child's cancer or tumour. For each question please cross X clearly inside one box using blue or black pen. If you have any questions, please call the helpline number 08000 720 069 or visit the survey website [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).

- Your feedback is important as it's the best way for us to understand your and your child's experience of cancer or tumour care.
- This survey is confidential and, if you decide to take part, none of the staff who cared for your child will know.
- Please do not write your name or address anywhere on the questionnaire.

**1** Which of the following best describes the current care or treatment relating to your child's cancer or tumour? **Please select all that apply.**

- 1 ☐ They have recently been diagnosed and are waiting for further information about next steps
- 2 ☐ They are in watch and wait
- 3 ☐ They are currently receiving treatment (e.g. to reduce or get rid of their cancer)
- 4 ☐ They have finished treatment within the last one month
- 5 ☐ They are in remission / long-term follow-up
- 6 ☐ They are receiving palliative or end of life care
- 7 ☐ They have recently passed away
- 8 ☐ Other



## FINDING OUT ABOUT YOUR CHILD'S CANCER OR TUMOUR

**If your child has had cancer or a tumour more than once, please think about the most recent time you were told when answering the following questions.**

**2** Was your child told they had cancer or a tumour within the last year?

- 1 ☐ Yes [Go to Question 3](#)
- 2 ☐ No [Go to Question 10](#)

**3** Before you were told your child needed to go to hospital about their cancer or tumour, how many times did they see a GP (family doctor) about the health problem caused by the cancer or tumour?

- 1 ☐ None - they went straight to hospital
- 2 ☐ They saw the GP once
- 3 ☐ They saw the GP twice
- 4 ☐ They saw the GP 3 or 4 times
- 5 ☐ They saw the GP 5 or more times
- 6 ☐ Don't know / can't remember

- 4** Was your child told they had cancer or a tumour at the hospital named in the letter that came with this questionnaire?

1 ☐ Yes [Go to Question 5](#)  
2 ☐ No [Go to Question 10](#)

- 5** How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?

1 ☐ I was seen as soon as I thought was necessary  
2 ☐ I should have been seen a bit sooner  
3 ☐ I should have been seen a lot sooner

- 6** Were you told about your child's cancer or tumour in a sensitive way?

1 ☐ Yes, definitely  
2 ☐ Yes, to some extent  
3 ☐ No  
4 ☐ Don't know / can't remember

- 7** When you were told about your child's cancer or tumour, was information given in a way that you could understand?

1 ☐ Yes, definitely  
2 ☐ Yes, to some extent  
3 ☐ No  
4 ☐ Don't know / can't remember

- 8** Were you able to have any questions answered by healthcare staff after you were told about your child's cancer or tumour?

1 ☐ Yes, definitely  
2 ☐ Yes, to some extent  
3 ☐ No  
4 ☐ I didn't have any questions  
5 ☐ Don't know / can't remember

- 9** Have you been able to find the information that you need about your child's diagnosis?

1 ☐ Yes, definitely  
2 ☐ Yes, to some extent  
3 ☐ No  
4 ☐ This was not needed

## HEALTHCARE STAFF

Please answer the following questions about any healthcare staff you have seen for your child's cancer or tumour in the last year at the hospital named in the covering letter.

- 10** Do staff caring for your child give you information in a way that you can understand?

1 ☐ Yes, definitely  
2 ☐ Yes, to some extent  
3 ☐ No

- 11** Have you had the chance to ask staff questions about your child's care and treatment?

1 ☐ Yes, definitely  
2 ☐ Yes, to some extent  
3 ☐ No  
4 ☐ I have not had any questions

- 12** Are you and your child treated with respect and dignity by staff?

1 ☐ Yes, always  
2 ☐ Yes, sometimes  
3 ☐ No

- 13** Do you have confidence and trust in the members of staff caring for your child?

1 ☐ Yes, always  
2 ☐ Yes, sometimes  
3 ☐ No

- 14** Do members of staff caring for your child treat you with empathy and understanding?

1 ☐ Yes, always  
2 ☐ Yes, sometimes  
3 ☐ No

- 15 Are you ever told different things by different members of staff, which leaves you feeling confused?

1 ☐ Yes, always  
2 ☐ Yes, sometimes  
3 ☐ No

- 16 Are staff sensitive to the information they share with you when your child is in the room?

1 ☐ Yes, always  
2 ☐ Yes, sometimes  
3 ☐ No  
4 ☐ This is not needed

- 17 Do healthcare staff share information with your child in a way that is appropriate for them?

1 ☐ Yes, always  
2 ☐ Yes, sometimes  
3 ☐ No  
4 ☐ This is not needed

- 18 Have hospital staff given you information about any of the following people you can chat to about your child's cancer or tumour?

**Please select all that apply.**

1 ☐ Charities (such as CLIC Sargent or Macmillan)  
2 ☐ A psychologist or counsellor  
3 ☐ Other parents of children with cancer or a tumour  
4 ☐ Other  
5 ☐ No, none of the above  
6 ☐ Don't know / can't remember

- 19 Do you have enough information about how to get financial help or any benefits you might be entitled to?

1 ☐ Yes, I have enough information  
2 ☐ Some, but not enough information  
3 ☐ No, but I would like this information  
4 ☐ This was not needed  
5 ☐ Don't know / can't remember

## YOUR CHILD'S CARE AND TREATMENT

Please answer these questions about the hospital named in the covering letter that came with this questionnaire.

- 20 In your opinion, do different hospital members of staff caring for your child work well together?

1 ☐ Yes, always  
2 ☐ Yes, sometimes  
3 ☐ No  
4 ☐ Don't know

- 21 Are different hospital members of staff caring for your child aware of your child's medical history?

1 ☐ Yes, definitely  
2 ☐ Yes, to some extent  
3 ☐ No  
4 ☐ Don't know / not applicable

- 22 Do you always know what is happening with your child's cancer or tumour care?

1 ☐ Yes, definitely  
2 ☐ Yes, to some extent  
3 ☐ No  
4 ☐ This is not needed

- 23 Are you involved as much as you want to be in decisions about your child's care and treatment?

1 ☐ Yes, definitely  
2 ☐ Yes, to some extent  
3 ☐ No  
4 ☐ No, but this is not needed or possible



**24** Has your child's schooling and education been impacted in any of the following ways by their treatment and care? **Please select all that apply.**

- 1 ☐ My child is not at school yet
- 2 ☐ My child's schooling or education hasn't been impacted
- 3 ☐ Being too unwell to attend school
- 4 ☐ Missing school due to timings of treatment and care
- 5 ☐ Poor concentration due to ill health or worries
- 6 ☐ Other

**25** Do you have a named member of staff who you can contact about your child's care and treatment at the hospital?

- 1 ☐ Yes
- 2 ☐ No

**26** Do you have access to reliable help and support 7 days a week from the hospital?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ This is not needed

**27** Is your child's care and treatment offered at a time suitable to you and your family (e.g. to fit in with education, employment or other needs)?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No, but I would have liked this
- 4 ☐ No, but this was not needed or possible

## TREATMENT

**28** Has your child received treatment for their cancer or tumour **in the last year**?

- 1 ☐ Yes [Go to Question 29](#)
- 2 ☐ No [Go to Question 34](#)

**29** Were you given clear written information about your child's treatment?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ This was not needed

**30** Did staff offer you enough time to make decisions about your child's treatment?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No, but I would have liked this
- 4 ☐ No, but this was not needed or possible

**31** Did staff offer support to help manage side effects from your child's treatment?

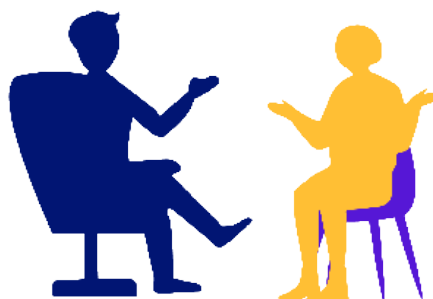
- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ This was not needed

**32** Have you been able to find the information that you need about your child's treatment at the hospital?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ This was not needed

**33** If your child's treatment has finished, did you receive enough ongoing support after it ended from the hospital?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ Not applicable / this was not needed
- 5 ☐ My child is still receiving treatment



## HOSPITAL WARD

Please answer the following questions about any hospital ward stays your child has had for cancer or tumour care at the hospital named in the covering letter that came with this questionnaire.

- 34** Has your child stayed on a **hospital ward** (as a day patient or for an overnight stay) for care relating to their cancer or tumour, in the last year?

1 ☐ Yes [Go to Question 35](#)  
2 ☐ No [Go to Question 46](#)

- 35** When your child was in hospital, were they able to get help from hospital staff when they needed it?

1 ☐ Yes, always  
2 ☐ Yes, sometimes  
3 ☐ No

- 36** Were there enough things for your child to do in the hospital?

1 ☐ Yes, definitely  
2 ☐ Yes, to some extent  
3 ☐ No  
4 ☐ This was not needed

- 37** Was there a choice of hospital food for your child?

1 ☐ Yes, definitely  
2 ☐ Yes, to some extent  
3 ☐ No  
4 ☐ My child did not have hospital food

- 38** Were you given somewhere private to talk to staff when your child was in hospital?

1 ☐ Yes, always  
2 ☐ Yes, sometimes  
3 ☐ No  
4 ☐ This was not needed

- 39** Did the hospital offer play specialist support for your child?

1 ☐ Yes  
2 ☐ No  
3 ☐ This was not needed

- 40** If your child stayed overnight, did you stay overnight with them?

1 ☐ Yes [Go to Question 41](#)  
2 ☐ No [Go to Question 43](#)  
3 ☐ My child did not stay overnight

[Go to Question 43](#)

- 41** How would you rate the facilities for parents or carers staying overnight?

1 ☐ Very good  
2 ☐ Good  
3 ☐ Fair  
4 ☐ Poor  
5 ☐ Very Poor

- 42** Was it quiet enough for you to sleep in the hospital?

1 ☐ Yes, always  
2 ☐ Yes, sometimes  
3 ☐ No  
4 ☐ I did not need to sleep in the hospital



**43** Were you able to prepare food in the hospital if you wanted to?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ I did not want to prepare food

**44** Did the hospital Wi-Fi meet your and your child's needs?

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No
- 4 ☐ This was not needed

**45** Did your child have access to hospital school services during their stay in hospital?

- 1 ☐ Yes
- 2 ☐ No
- 3 ☐ This was not needed

## CARE AT HOME

**46** Have you been visited at home by a nurse in the last year, for care for your child's cancer or tumour?

- 1 ☐ Yes [Go to Question 47](#)
- 2 ☐ No [Go to Question 50](#)
- 3 ☐ Don't know / can't remember

[Go to Question 50](#)

**47** Were the nurses that came to your home friendly?

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No
- 4 ☐ Don't know / can't remember

**48** When nurses speak to you, do you understand what they are saying?

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No
- 4 ☐ Don't know / can't remember

**49** Did the same nurses come to your home?

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No
- 4 ☐ Don't know / can't remember
- 5 ☐ I have only been visited once



## OVERALL

- 50 Do different hospitals providing your child's cancer or tumour care work well together?

- 1 ☐ Yes, always  
2 ☐ Yes, sometimes  
3 ☐ No  
4 ☐ My child does not receive care at different hospitals

- 51 Is the hospital where your child receives most of their cancer or tumour care under one hours travel from their home?

- 1 ☐ Yes  
2 ☐ No

- 52 Overall ... (please circle a number)

0 1 2 3 4 5 6 7 8 9 10

My child's cancer or tumour care is very poor

My child's cancer or tumour care is very good

## ABOUT YOUR CHILD

- 53 Is your child male or female?

- 1 ☐ Male  
2 ☐ Female  
3 ☐ Prefer not to say

- 54 How old is your child?

years old

- 55 Which of these best describes your child's ethnic background? (Cross ONE only)

### A. WHITE

- 1 ☐ English / Welsh / Scottish / Northern Irish / British  
2 ☐ Irish  
3 ☐ Gypsy or Irish Traveller  
4 ☐ Any other White background

### B. MIXED / MULTIPLE ETHNIC GROUPS

- 5 ☐ White and Black Caribbean  
6 ☐ White and Black African  
7 ☐ White and Asian  
8 ☐ Any other mixed or multiple ethnic background

### C. ASIAN / ASIAN BRITISH

- 9 ☐ Indian  
10 ☐ Pakistani  
11 ☐ Bangladeshi  
12 ☐ Chinese  
13 ☐ Any other Asian background

### D. BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH

- 14 ☐ African  
15 ☐ Caribbean  
16 ☐ Any other Black / African / Caribbean background

### E. OTHER ETHNIC GROUP

- 17 ☐ Arab  
18 ☐ Any other ethnic group

- 56 Other than your child's cancer or tumour, do they have any **unrelated** physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more?

- 1 ☐ Yes  
2 ☐ No



## ANYTHING ELSE TO SAY?

- 57 Is there anything else you would like to tell us about your child's cancer or tumour care (e.g. anything particularly good; anything that could be improved), please do so here.

Please note that the comments you provide in the box above will be looked at in full by the hospital, NHS England and NHS Improvement and researchers working with the data. We will remove any information that could identify you before publishing any of your feedback.

**Please post this questionnaire back in the FREEPOST envelope.  
NO STAMP IS NEEDED.**

