

# Under 16 Cancer Patient Experience Survey CHILDREN'S SECTION

**These questions are about the care you received for your cancer or tumour**

For each question please cross X clearly inside one box using blue or black pen. If you have any questions, please ask your parent or carer, call the helpline number 08000 720 069 or visit the survey website [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).

- Your answers will help to make children's cancer and tumour care the best it can be.
- We will make sure that nobody can tell which answers are yours. Please do not write your name or address anywhere on the questionnaire.
- You're the expert in what your care is like, so please tell us what you think.

## FINDING OUT ABOUT YOUR CANCER OR TUMOUR

If you have had cancer or a tumour more than once, please think about the most recent time when answering the following questions.

- 1** Were you told you had cancer or a tumour within the last year?
- 1  Yes [Go to Question 2](#)
- 2  No [Go to Question 6](#)
- 
- 2** Were you told you had cancer or a tumour at the hospital named in the letter that came with this questionnaire?
- 1  Yes [Go to Question 3](#)
- 2  No [Go to Question 6](#)
- 
- 3** When you were told about your cancer or tumour, was information given in a way that you could understand?
- 1  Yes, definitely
- 2  Yes, sort of
- 3  No
- 4  Don't know / can't remember

- 4** Were you able to have any questions answered by healthcare staff after you were told about your cancer or tumour?
- 1  Yes, definitely
- 2  Yes, sort of
- 3  No
- 4  I did not have any questions
- 5  Don't know / can't remember

- 5** Did hospital staff give you details for who to contact if you wanted more information after you were told about your cancer or tumour?
- 1  Yes
- 2  No
- 3  Don't know / can't remember

## HEALTHCARE STAFF

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

- 6** Do you feel that staff are friendly?
- 1  Yes, always
- 2  Yes, sometimes
- 3  No



7 When staff 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

8 Do staff speak to you in a way that is suitable for you?

- 1 😊  Yes, always
- 2 😊  Yes, sometimes
- 3 😞  No

9 Do staff talk to you, not just to your parent or carer?

- 1 😊  Yes, always
- 2 😊  Yes, sometimes
- 3 😞  No

10 Do you see the same members of staff for your treatment and care?

- 1 😊  Yes, always or mostly
- 2 😊  Yes, sometimes
- 3 😞  No

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

- 1 😞  Yes, always
- 2 😊  Yes, sometimes
- 3 😊  No

12 Have hospital staff given you information about any of the following people you can chat to about your cancer or tumour? **Please select all that apply.**

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

## YOUR CARE AND TREATMENT

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

13 Do you always know what is happening with your cancer or tumour care?

- 1 😊  Yes, definitely
- 2 😊  Yes, sort of
- 3 😞  No
- 4 😞  This is not needed

14 Do you have a say in deciding what happens with your care?

- 1 😊  Yes, definitely
- 2 😊  Yes, sort of
- 3 😞  No
- 4 😞  No, but this is not needed or possible

## HOSPITAL WARD

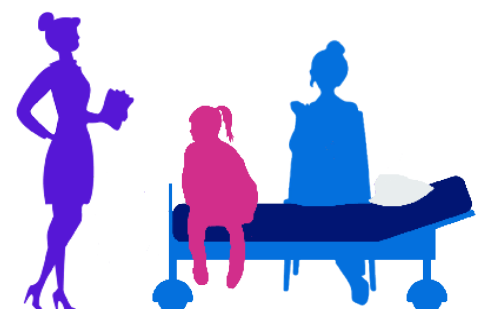
Please answer the following questions about any hospital ward stays you have had for cancer or tumour care at the hospital named in the covering letter that came with this questionnaire.

15 Have you stayed on a hospital ward (as a day patient or for an overnight stay) for care about your cancer or tumour, in the last year?

- 1  Yes [Go to Question 16](#)
- 2  No [Go to Question 21](#)

16 When you were in hospital, were you able to get help from hospital staff when you needed it?

- 1 😊  Yes, always
- 2 😊  Yes, sometimes
- 3 😞  No



17 Were there enough things for you to do in the hospital?

- 1 😊  Yes, definitely
- 2 😐  Yes, sort of
- 3 ☹️  No
- 4 😞  This was not needed

18 Was there a choice of hospital food?

- 1 😊  Yes, definitely
- 2 😐  Yes, sort of
- 3 ☹️  No
- 4 😞  I did not have hospital food

19 Were you given somewhere private to talk to staff when you were in hospital?

- 1 😊  Yes, always
- 2 😐  Yes, sometimes
- 3 ☹️  No
- 4 😞  This was not needed

20 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

## CARE AT HOME

21 Have you been visited at home by a nurse in the last year, for care for your cancer or tumour?

- 1  Yes [Go to Question 22](#)
- 2  No [Go to Question 25](#)
- 3  Don't know / can't remember

[Go to Question 25](#)

22 Were the nurses that came to your home friendly?

- 1 😊  Yes, always
- 2 😐  Yes, sometimes
- 3 ☹️  No
- 4 😞  Don't know / can't remember

23 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

24 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

25 Overall, how well are you looked after for your cancer or tumour by the healthcare staff?

- 1 😊  Very well
- 2 😐  Quite well
- 3 😐  OK
- 4 ☹️  Not very well
- 5 ☹️  Not at all well

## ABOUT YOU

26 Are you a boy or a girl?

- 1  Boy
- 2  Girl
- 3  I do not want to say

27 How old are you today?

years old



## ANYTHING ELSE TO SAY?

- 28 Is there anything else you wanted to tell us about your cancer or tumour care (anything good, or anything that could be better)?

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 now hand this survey to your parent or carer so they can fill out the following questions.**

## PARENT/CARER SECTION

Please note that these questions are about your child's cancer or tumour care.

- 29 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.**

- 30 Was your child told they had cancer or a tumour within the last year?
- 1  Yes [Go to Question 31](#)
  - 2  No [Go to Question 36](#)
- 
- 31 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

**32** 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 33](#)  
2  No [Go to Question 36](#)

**33** 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

**34** 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

**35** 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.**

**36** 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

**37** 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

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

- 1  Yes, always  
2  Yes, sometimes  
3  No

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

- 1  Yes, always  
2  Yes, sometimes  
3  No

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

- 1  Yes, always  
2  Yes, sometimes  
3  No

**41** 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

**42** 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

**43** 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

- 44 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.

- 45 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

- 46 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

- 47 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's schooling or education hasn't been impacted
  - 2  Being too unwell to attend school
  - 3  Missing school due to timings of treatment and care
  - 4  Poor concentration due to ill health or worries
  - 5  Other

- 48 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

- 49 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

- 50 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

- 51 Has your child's care or treatment changed what they are normally able to do, such as seeing friends, doing hobbies or going to school?
- 1  Yes, definitely [Go to Question 52](#)
  - 2  Yes, to some extent [Go to Question 52](#)
  - 3  No [Go to Question 53](#)

- 52 Have you spoken to staff about this?
- 1  Yes
  - 2  No, but I would like to
  - 3  This is not needed

## TREATMENT

- 53 Has your child received treatment for their cancer or tumour **in the last year?**
- 1  Yes [Go to Question 54](#)
  - 2  No [Go to Question 59](#)

- 54 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

- 55 Did staff offer you enough time to make decisions about your child's treatment?
- Yes, definitely
  - Yes, to some extent
  - No, but I would have liked this
  - No, but this was not needed or possible

- 56 Did staff offer support to help manage side effects from your child's treatment?
- Yes, definitely
  - Yes, to some extent
  - No
  - This was not needed

- 57 Have you been able to find the information that you need about your child's treatment at the hospital?
- Yes, definitely
  - Yes, to some extent
  - No
  - This was not needed

- 58 If your child's treatment has finished, did you receive enough ongoing support after it ended from the hospital?
- Yes, definitely
  - Yes, to some extent
  - No
  - Not applicable / this was not needed
  - 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.

- 59 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?
- Yes [Go to Question 60](#)
  - No [Go to Question 65](#)

- 60 If your child stayed overnight, did you stay overnight with them?
- Yes [Go to Question 61](#)
  - No [Go to Question 62](#)
  - My child did not stay overnight  
[Go to Question 62](#)

- 61 How would you rate the facilities for parents or carers staying overnight?
- Very good
  - Good
  - Fair
  - Poor
  - Very Poor

- 62 Were you able to prepare food in the hospital if you wanted to?
- Yes, definitely
  - Yes, to some extent
  - No
  - I did not want to prepare food

- 63 Did the hospital Wi-Fi meet your and your child's needs?
- Yes, always
  - Yes, sometimes
  - No
  - This was not needed

- 64 Did your child have access to hospital school services during their stay in hospital?
- Yes
  - No
  - This was not needed

## OVERALL

- 65 Do different hospitals providing your child's cancer or tumour care work well together?
- Yes, always
  - Yes, sometimes
  - No
  - My child does not receive care at different hospitals

66 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

67 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

68 Who was the main person who answered the questions in the **children's section** of the questionnaire?

- 1  The child / young patient  
2  The parent or carer  
3  Both the child / young patient and the parent or carer together

## ABOUT YOUR CHILD

69 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

70 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

## ANYTHING ELSE TO SAY?

71 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.

