

Under 16 Cancer Patient Experience Survey

These questions are about the care received 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 ask your parent or carer, call the helpline number 08000 720 069 or visit the survey website 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 (child's) care is like, so please tell us what you think.
- You can skip any questions you do not want to answer.
- There is a text box later in the survey for any further comments about your (child's) care.

CHILDREN'S/ YOUNG PERSON'S SECTION

FINDING OUT ABOUT YOUR CANCER OR TUMOUR

Please think about the time your cancer or tumour was confirmed. If you have had cancer or a tumour more than once, please think about the most recent time you were told in the following questions.

- 1 Were you told you had cancer or a tumour during 2021?

- 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 during 2021 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 Do staff speak to you in a way that you can understand?

- 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 Young Lives vs Cancer 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 care received during 2021 at the hospital named in the covering letter.

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 Are you involved in decisions about your care and treatment?

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

15 Has your care or treatment changed what you are normally able to do, such as seeing friends, doing hobbies or going to school?

- 1 Yes, definitely Go to Question 16
- 2 Yes, sort of Go to Question 16
- 3 No Go to Question 17

16 Have you spoken to staff about this?

- 1 Yes
- 2 No, but I would like to
- 3 This is not needed

CARE IN HOSPITAL

Please answer the following questions about any hospital stays you have had for cancer or tumour care at the hospital named in the covering letter.

17 Have you stayed in hospital during 2021 (receiving treatment or care in the daytime, or for an overnight stay)?

- 1 Yes Go to Question 18
- 2 No Go to Question 23

18 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

19 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

20 Was there a choice of hospital food?

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

21 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

22 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 OR SCHOOL

23 Have you been visited at home or school by a nurse during 2021, for care for your cancer or tumour?

- 1 Yes Go to Question 24
- 2 No Go to Question 27
- 3 Don't know / can't remember

Go to Question 27

24 Were the nurses that came to your home or school friendly?

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

25 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

26 Did the same nurses come to your home or school?

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

OVERALL

27 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

28 Do different hospitals providing your cancer or tumour care work well together?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 I don't receive care at different hospitals



ABOUT YOU

29 Are you a boy or a girl?

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

30 How old are you today?

years old

ANYTHING ELSE TO SAY?

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

CONFIDENTIAL

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 to fill out the following questions.

PARENT/CARER

SECTION

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

FINDING OUT ABOUT YOUR CHILD'S CANCER OR TUMOUR

Please think about the time your child's cancer or tumour was confirmed. If your child has had cancer or a tumour more than once, please think about the most recent time you were told in the following questions.

32 Were you told about your child's cancer or tumour during 2021?

- 1 Yes Go to Question 33
- 2 No Go to Question 38

33 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

34 Were you told about your child's cancer or tumour at the hospital named in the letter that came with this questionnaire?

- 1 Yes Go to Question 35
- 2 No Go to Question 38

35 How do you feel about the length of time you had to wait before your child's first appointment with a hospital doctor?

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

36 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

37 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 during 2021 at the hospital named in the covering letter.

38 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

39 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

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

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



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

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

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

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

43 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

44 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

45 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 Young Lives vs Cancer 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

- 46** 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 care received during 2021 at the hospital named in the covering letter.

- 47** In your opinion, do different hospital staff caring for your child work well together?
- 1 Yes, always
2 Yes, sometimes
3 No
4 Don't know

- 48** Are different hospital 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

- 49** 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 has not 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 Tiredness or fatigue
6 Other

- 50** 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
- 51** 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

- 52** 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

- 53** Has your child received treatment for their cancer or tumour during 2021?
- 1 Yes Go to Question 54
2 No Go to Question 58

- 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?
- 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

56 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

57 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

CARE IN HOSPITAL

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

58 Has your child stayed in hospital during 2021 (receiving treatment or care in the daytime, or for an overnight stay)?

- 1 Yes [Go to Question 59](#)
- 2 No [Go to Question 64](#)

59 If your child stayed overnight, did you stay overnight with them?

- 1 Yes [Go to Question 60](#)
- 2 No [Go to Question 61](#)
- 3 My child did not stay overnight

[Go to Question 61](#)

60 How would you rate the facilities for parents or carers staying overnight?

- 1 Very good
- 2 Good
- 3 Fair
- 4 Poor
- 5 Very poor

61 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

62 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

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

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

OVERALL

64 How long does it take to get to the hospital where your child receives most of their cancer or tumour care?

- 1 Under an hour
- 2 About an hour
- 3 Over an hour

65 Overall ... (please circle a number)



My child's cancer
or tumour care is
very poor

My child's cancer
or tumour care is
very good

66 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

67 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

68 Does your child have any **unrelated** physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more, other than their cancer or tumour?

- 1 Yes
- 2 No

69 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 Other

ANYTHING ELSE TO SAY?

70 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)?

OPTIONAL

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.

Thank
you!