

Under 16 Cancer Patient Experience Survey PARENT / CARER 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 call the helpline number 08000 720 069 or visit the survey website 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.
 - 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.

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 when answering the following questions.

1 Were you told about your child's cancer or tumour during 2022?

- 1 Yes Go to Question 2
2 No Go to Question 9

2 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(s) 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

3 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 4
2 No Go to Question 9

4 How did you feel about the length of time you waited between being referred by your GP to a hospital doctor until you were seen at the hospital?

- 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
4 We were not referred by a GP

5 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



- 6 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

- 7 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 did not have any questions
 - 5 Don't know / can't remember

- 8 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 saw for your child's cancer or tumour during 2022 at the hospital named in the covering letter.

- 9 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

- 10 Are you and your child treated with respect and dignity by staff?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No

- 11 Do you have confidence and trust in the members of staff caring for your child?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No

- 12 Do members of staff caring for your child treat you with empathy and understanding?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No

- 13 Are you ever told different things by different members of staff, which leaves you feeling confused?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No

- 14 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

- 15 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

- 16** 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

- 17** 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 2022 at the hospital named in the covering letter.

- 18** 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

- 19** 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

- 20** 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

- 21** Are you involved as much as you wanted 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

- 22** Has your child's schooling and education (including pre-school) been impacted in any of the following ways by their treatment and care? **Please select all that apply.**

- 1 My child is not at pre-school or has not started school
2 My child's schooling or education has not been impacted
3 Being too unwell to attend school, pre-school or home schooling
4 Missing school, pre-school or home schooling due to timings of treatment and care
5 Poor concentration due to ill health or worries
6 Tiredness or fatigue
7 Other

- 23** Did you have a main person in the team looking after your child (such as a specialist nurse or key worker) who you could contact about their care and treatment?

- 1 Yes [Go to Question 24](#)
2 No [Go to Question 25](#)

24 How easy was it for you to contact this person?

- 1 Very easy
- 2 Quite easy
- 3 Neither easy nor difficult
- 4 Quite difficult
- 5 Very difficult
- 6 I have not tried to contact them

25 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

26 Did staff do what they could to make the timing of your child's care and treatment suitable for you and your family (e.g. to fit in with education, employment and 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

27 Has your child received treatment for their cancer or tumour during 2022?

- 1 Yes [Go to Question 28](#)
- 2 No [Go to Question 32](#)

28 Were you offered clear information about your child's treatment?

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



29 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

30 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

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

- 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 and treatment [at the hospital named in the covering letter](#).

32 Has your child stayed in hospital during 2022 (receiving treatment or care in the daytime, or for an overnight stay)?

- 1 Yes [Go to Question 33](#)
- 2 No [Go to Question 44](#)

33 When your child was in hospital, were they able to get help from staff on the ward when they needed it?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 They did not need any help
- 5 Don't know / can't remember

34 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

35 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

36 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

37 Was play support available in hospital when your child needed it (i.e. from a Health Play Specialist who uses play and activities to support patients and/or prepare them for treatments)?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 My child did not need this

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

- 1 Yes [Go to Question 39](#)
- 2 No [Go to Question 41](#)
- 3 My child did not stay overnight

[Go to Question 41](#)

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

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

40 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

41 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

42 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

43 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 OR AT SCHOOL

44 Has your child been visited at home or school by a nurse during 2022 for care for their cancer or tumour?

- 1 Yes [Go to Question 45](#)
2 No [Go to Question 48](#)
3 Don't know [Go to Question 48](#)

45 Were the nurses that came to your home or your child's school friendly?

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

46 When nurses speak to you, do you understand what they were saying?

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

47 Did the same nurses come to your home or your child's school?

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



OVERALL

48 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

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

- 1 About an hour or under
2 Over an hour

50 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

The next questions will help tell us more about your child, and how experiences might vary between different groups.

51 What sex was your child registered at birth?

- 1 Male
2 Female
3 Prefer not to say

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

A. **WHITE**

- 1 English, Welsh, Scottish, Northern Irish or British
- 2 Irish
- 3 Gypsy or Irish Traveller
- 4 Roma
- 5 Any other White background

B. **MIXED / MULTIPLE ETHNIC GROUPS**

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

C. **ASIAN / ASIAN BRITISH**

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

D. **BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH**

- 15 African
- 16 Caribbean
- 17 Any other Black / African / Caribbean background

E. **OTHER ETHNIC GROUP**

- 18 Arab
- 19 Any other ethnic group

53 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

54 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?

55 Is there anything else you would like to tell us about your child's cancer or tumour care?

Was there anything particularly good?

Was there anything that could be improved on?

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

If you would like to make a complaint about your child's care, please contact your hospital directly.

Further advice and support for children with cancer, and their family members, can be found here: www.under16cancerexperiencesurvey.co.uk/help-support.

Please post this questionnaire back in the FREEPOST envelope.

NO STAMP IS NEEDED.

**Thank
you!**