



**UNDER 16 CANCER PATIENT EXPERIENCE  
SURVEY  
COMMUNICATIONS TOOLKIT**

## About the Under 16 Cancer Patient Experience Survey

In 2020 NHS England and Improvement launched a national survey to measure the experience of children and young people under the age of 16 in care and treatment for cancer. This survey builds on the success of the National Cancer Patient Experience Survey but recognises that cancer care pathways and care priorities for children often differ to adults, and therefore a unique approach is required to understand their experiences of cancer care and treatment.

The results from the survey provides national-level insight into the experiences of children with cancer and will inform how the NHS delivers cancer services going forward.

Fieldwork for those treated in 2021 will commence in April 2022, with the results due for release in autumn 2022.

The first phase of communication is designed to raise awareness of the survey and encourage those who are invited to take part.

## About the toolkit

This toolkit provides a range of assets you can use to help spread the word about the survey and encourage participation. In the toolkit you will find:

- 1) Key messages
- 2) Core text (to be used for newsletters and blogs)
- 3) Logo assets
- 4) Suggested social media copy
- 5) FAQs
- 6) Printable poster (see attached)

If you have any questions on the information in this document or would like guidance on communications please contact [england.cancercomms@nhs.net](mailto:england.cancercomms@nhs.net).

## 1) Key messages

- The Under 16 Cancer Patient Experience Survey (U16 CPES) measures the experiences of tumour and cancer care in children across England.
- The Under 16 Cancer Patient Experience Survey will inform how the NHS delivers cancer services with the aim to radically improve the outcomes for children and young people affected by cancer.
- Those working within cancer services will use the results to assess performance both locally and nationally, to help identify priority areas for enhancing the experience of children's cancer services.
- Experience of care for people who use NHS services is extremely important and we understand the need for personalised care and treatment. By contributing to the survey, you will help the NHS to continue to improve services.

## 2) Core text (to be used for newsletters and blogs)

### Short

A diagnosis of childhood cancer understandably has a devastating impact on the emotional health and wellbeing of the child and their family, both during and after treatment. Children and young people's treatment and experience of cancer differs greatly from adults and we recognise the need for a personalised approach to their cancer care.

It's so important for us to listen and learn from children and young people in order to provide them with the best possible care and experience throughout treatment and to reduce the impact it has on them later in life.

The Under 16 Cancer Patient Experience Survey will inform how the NHS delivers cancer services with the aim to radically improve the outcomes for children and young people affected by cancer.

The NHS really wants to hear from children and young people, and their families, about their experiences so that we can continue to improve the care and services the NHS delivers. If you receive an invitation in the post please complete the survey.

For more information visit [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).

### Long

A diagnosis of childhood cancer understandably has a devastating impact on the emotional health and wellbeing of the child and their family, both during and after treatment. Children and young people's treatment and experience of cancer differs greatly from adults and we recognise the need for a personalised approach to their cancer care.

It's so important for the NHS to listen and learn from children and young people in order to provide them with the best possible care and experience throughout treatment and to reduce the impact it has on them later in life.

We want to hear from children and young people, and their families, about their experiences so that we can continue to improve the care and services the NHS delivers.

The Under 16 Cancer Patient Experience Survey builds on the work of the National Cancer Patient Experience Survey, understanding that cancer care pathways and care priorities for children and young people often differ to adults.

The results from the survey, which were made available in Autumn 2021, provided the first national-level insight into the experiences of children with cancer and will inform how the NHS delivers cancer services going forward. Commissioners, providers and national policymakers are using the results to

assess performance both locally and nationally, to help identify priority areas for enhancing children's cancer services. The aim is to radically improve the outcomes for children and young people affected by cancer.

Our intention now is to run the survey every year. The second wave of the survey is being implemented across England from March 2022. Children under 16 who received NHS cancer care during 2021 and their parents or carers will be invited to participate. They will be able to complete a paper questionnaire or an online version of the survey on any device.

Experience of care for people who use our services is extremely important and the need for personalised care and treatment is well recognised. By contributing to the survey, young people and their parents or carers will help the NHS to continue to improve its services and better support children and young people living with and beyond cancer.

For more information on the survey visit [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).

### 3) Logo assets

Master logo



Twitter logo



[Under16CancerExperienceSurvey.co.uk](http://Under16CancerExperienceSurvey.co.uk)

Facebook logo



[Under16CancerExperienceSurvey.co.uk](https://Under16CancerExperienceSurvey.co.uk)

#### Web banner



[Under16CancerExperienceSurvey.co.uk](https://Under16CancerExperienceSurvey.co.uk)

#### 4) Social media

When posting on social media about the survey please use the hashtag #U16CancerPatientSurvey and tag @NHSEngland where possible please also tag @pickereurope.

Below you will find suggested copy for:

- Twitter
- Facebook
- Instagram stories
- Instagram post
- LinkedIn

##### Twitter

We want to listen & learn from the experiences of young people diagnosed with cancer in order to improve the care & support the NHS provides. The [#U16CancerPatientSurvey](#) informs how we deliver cancer services for children & young people [www.under16cancerexperiencesurvey.co.uk](https://www.under16cancerexperiencesurvey.co.uk).

In order to provide the best possible care for young people diagnosed with cancer it's important for us to listen & learn from their experiences. The [#U16CancerPatientSurvey](#) informs how we deliver cancer services [www.under16cancerexperiencesurvey.co.uk](https://www.under16cancerexperiencesurvey.co.uk).

Have your voice heard. Children under the age of 16 cared or treated for cancer in 2021 and their parents/carers are being invited to take part in a survey to help with the continued improvement of cancer care for young people. @NHSEngland #U16CancerPatientSurvey [www.under16cancerexperiencesurvey.co.uk](https://www.under16cancerexperiencesurvey.co.uk).

The U16 Cancer Patient Experience Survey informs how the NHS delivers cancer services and aims to improve outcomes for children affected by cancer. If you're invited to take part, please have your say @NHSEngland #U16CancerPatientSurvey [www.under16cancerexperiencesurvey.co.uk](https://www.under16cancerexperiencesurvey.co.uk)

##### Facebook

A diagnosis of childhood cancer understandably has a devastating impact on the emotional health and wellbeing of the child and their family, both during and after treatment. We want to listen and learn from the experiences of children diagnosed with cancer in order to improve the care and support the NHS provides. The U16 Cancer Patient Experience Survey informs how we deliver cancer services for children and young people. If you receive a survey please take part. For more information visit [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).

Children's treatment and experience of cancer differs greatly from adults and we recognise the need for a personalised approach to children's cancer care. In order to continue to improve the services we provide we want to listen and learn from the experiences of children diagnosed with cancer. If invited, have your voice heard by completing the U16 Cancer Patient Experience Survey. For more information visit [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).

Help the improvement of cancer services for young people and have your say. Children under the age of 16 cared or treated for cancer in 2021 and their parents/carers are being invited to take part in a survey to help with the continued improvement of cancer care for young people. If you're invited to take part please have your say. #U16CancerPatientSurvey  
[www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).

#### Instagram stories

**Story one** - A diagnosis of childhood cancer understandably has a devastating impact on the emotional health and wellbeing of the child and their family, both during and after treatment. (Link to [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).)

**Story two** - Children's treatment and experience of cancer differs greatly from adults and we recognise the need for a personalised approach to children's cancer care. (Link to [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).)

**Story three** - We want to listen and learn from the experiences of children diagnosed with cancer in order to improve the care and support the NHS provides. The U16 Cancer Patient Experience Survey informs how we deliver cancer services for children and young people. (Link to [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).)

**Story four** - The results will inform cancer services going forward and help improve the outcomes for children affected by cancer. If you're invited to take part, please have your say and help us improve our services by taking part. (Link to [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).)

#### Instagram post

A diagnosis of childhood cancer understandably has a devastating impact on the emotional health and wellbeing of the child and their family, both during and after treatment. We want to listen and learn from the experiences of children diagnosed with cancer in order to improve the care and support the NHS provides. The U16 Cancer Patient Experience Survey informs how we deliver cancer services for children and young people.

#U16CancerPatientSurvey #cancercare #childrenwithcancer

#### LinkedIn

The U16 Cancer Patient Experience Survey helps us to understand and improve the care and experience for children under the age of 16 in care and treatment for cancer.

The results from the Under 16 Cancer Patient Experience Survey provide national-level insight into the experiences of children with cancer and inform how the NHS delivers cancer services going forward. The aim is to radically improve the outcomes for children and young people affected by cancer.

Children treated in 2021 and their parents or carers will be invited to take part in the survey from April 2022. For more information on the survey visit [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).

## 5) FAQs

### **Q. Why was I invited to take part?**

A. Anyone under the age of 16 (at the time of their care or treatment) who has received treatment or care relating to cancer during 2021 is being invited to take part. This includes children (and their parents/carers) who currently have cancer, have had cancer in the past but are now better/in remission/ recovered, and are receiving follow-up care, have had cancer in the past but are now better/in remission/ recovered, and have recently had an appointment, hospital visit, operation or procedure in relation to their past cancer, have a non-malignant brain, other central nervous system or intracranial tumour, or non-cancerous blood disease. If you need any further guidance please contact [under16cancersurvey@PickerEurope.ac.uk](mailto:under16cancersurvey@PickerEurope.ac.uk)

### **Q. I wasn't invited to take part but am interested in providing feedback**

A. There are other ways to give feedback if you weren't included in the survey. Feedback can be provided through the Patient Advice and Liaison Service (PALS) or patient experience team for the NHS Trust where you or your child received care. A list of relevant contacts can be found at <https://www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/>. You might also want to consider using the Friends and Family Test to give quick, anonymous feedback. Any member of staff at the Trust should be able to tell you how.

### **Q. When will survey results be available?**

A. Survey results will be made available on this website in the autumn, as soon as possible after data has been collected from patients, allowing time for paper surveys to be returned and the data to be quality checked.

### **Q. Can I complete the survey in any other languages?**

A. Yes, Picker Institute Europe, which carries out the survey on behalf of NHS England and NHS Improvement, offers an interpretation service, where the questionnaire can be filled in over the telephone with someone who speaks your language. Please call 08000 720 069 to use this service.

### **Q. Can someone help me complete the survey?**

A. Picker Institute Europe, which carries out the survey on behalf of NHS England and NHS Improvement, provides a Freephone helpline (08000 720 069) where call advisors are available to complete the survey with children and parents over the telephone.

### **Q. How can I find more about the survey?**

A. You can find more information about the survey, including how it was developed at [www.under16cancerexperiencesurvey.co.uk/about-survey](http://www.under16cancerexperiencesurvey.co.uk/about-survey)

### **Q. How do I complete the questionnaire?**

A. You can complete the paper questionnaire that has been sent to your postal address, and send it back in the freepost envelope provided, you can complete the online version of the survey or you can complete it over the telephone by calling the Freephone helpline (08000 720 069).

### **Q. How did you get my personal details such as my name and address?**

A. Your personal details and some information about your cancer treatment have been used to identify you for this survey and will be used to analyse the results. These details were provided by the NHS trust that treated you. The details have been shared with Picker Institute Europe, who are carrying out the survey on behalf of NHS England and NHS Improvement. Under data protection legislation NHS England and NHS Improvement is the controller responsible for the processing of your personal data to conduct the survey. Your personal information will be handled securely, and the results published will not identify you.

### **Q. I have received a questionnaire, however I don't have cancer**

A. Anyone who has received treatment or care relating to cancer in 2021 could receive a survey. This includes children (and their parents/carers) who currently have cancer, have had cancer in the past

but are now better/in remission/ recovered, and are receiving follow-up care, have had cancer in the past but are now better/in remission/ recovered, and have recently had an appointment, hospital visit, operation or procedure in relation to their past cancer, have a non-malignant brain, other central nervous system or intracranial tumour, or non-cancerous blood disease.

If you do not think you (or your child) should have received a survey, please contact Picker on the freephone helpline (08000 720 069).

**Q. If I take part, do I have to answer every question?**

A. No. You don't have to answer every question if you don't want to.

**Q. I've lost my paper questionnaire, what do I do?**

A. If this is the first time you received the questionnaire you will soon receive a second copy. Alternatively you can contact Picker by email ([under16cancersurvey@PickerEurope.ac.uk](mailto:under16cancersurvey@PickerEurope.ac.uk)) or phone 08000 720 069

**Q. What happens to my answers?**

A. Your answers are put together with the answers from other people who take part. Your individual answers to the questions will be kept confidential and nobody will be able to identify you in any results that are published. The results will be published on the website (<https://www.under16cancerexperiencesurvey.co.uk/>) under the 'results' page.

**Q. Who is running the survey?**

A. Picker Institute Europe is carrying out the survey on behalf of NHS England and NHS Improvement.

**Q. Why can't people over the age of 16 with cancer take part?**

A. People aged 16 and over who have been treated for cancer during a specified time period are invited to take part in a separate survey called the National Cancer Patient Experience Survey. For more information about this survey, please visit <https://www.ncpes.co.uk/>