

# Under 16 Cancer Patient Experience Survey 2023: Communications Toolkit & Guidance

## About the Under 16 Cancer Patient Experience Survey

In 2020, NHS England 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 who received cancer-related care and treatment in 2023 will commence in April 2024, with the results due for release in autumn 2024. NHS England are working with Picker to deliver this survey.

## About the toolkit

This Communications Toolkit is designed to help you raise awareness of the survey and encourage those who are invited to take part to respond. It provides a range of assets you can use to help spread the word about the survey and encourage participation. **There was a substantial reduction in response rate to the survey between the first two years, therefore we strongly encourage you to use this toolkit to raise awareness of the survey to help maximise response rates.**

In the toolkit you will find:

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

If you have any questions on the information in this document or would like guidance on communications, please contact [under16cancersurvey@pickereurope.ac.uk](mailto:under16cancersurvey@pickereurope.ac.uk).

## 1) Key messages

- The Under 16 Cancer Patient Experience Survey (U16 CPES) measures the experiences of NHS tumour and cancer care in children across England.
- The Under 16 Cancer Patient Experience Survey informs 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 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 informs 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 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 survey has been running since 2020 and the results provide national-level insight into the experiences of children with cancer and informs how the NHS delivers cancer services going forward. Commissioners, providers, and national policymakers use 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.

The fourth wave of the survey is being implemented across England from April 2024. Children under 16 who received NHS cancer care during 2023 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 and image/poster assets

We have produced a range of assets in a few design options to support staff engagement, HR, and comms colleagues in promoting the survey to their staff through their own internal communications and engagement channels. This includes assets suitable to those working on site and for digital/online.

#### Master logo



#### Assets

- **X (formerly Twitter) Images**
- **LinkedIn/Facebook Images**
- **Instagram Images**
- **Instagram stories**
- **Email signature promo banners:** To be added to email signatures.
- **Printable posters:** These have been designed for Principal Treatment Centres (PTCs) to display in children's cancer wards and waiting rooms.
- **Video:** This is designed for social media but could potentially be used to be displayed on TV screens in hospital waiting rooms.
- **Patient Letter Footer:** These are to be added to the footer of patient letters.

All the assets detailed above are hosted on here: [Survey Support Materials](#)

- [X \(formerly Twitter\) Images](#)
- [LinkedIn/Facebook Images](#)
- [Instagram Images](#)
- [Instagram stories](#)
- [Email signature promo banners](#)
- [Printable posters](#)
- [Video](#)
- [Patient Letter Footer](#)

## 4) Social media

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

Here is a [short video](#) for you to share on your social media channels.

Below you will find suggested copy for:

- X (formerly Twitter)
- Facebook
- Instagram stories
- Instagram post
- LinkedIn

### X (formerly Twitter)

1. We want to listen & learn from the experiences of young people diagnosed with cancer to improve the care & support the NHS provides. Take part in the [#U16CancerPatientSurvey](#) to help us develop cancer services for children & young people.  
[www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).
2. 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. [@NHSEngland](#) [@PickerEurope](#)  
[www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).
3. Children aged 16 and under cared for or treated for cancer in 2023 and their parents/carers, are being invited to take part in a survey to help improve cancer care services.  
[@NHSEngland](#) [#U16CancerPatientSurvey](#) [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).
4. The Under 16 Cancer Patient Experience Survey informs how the NHS delivers cancer services and aims to improve outcomes for children affected by cancer. If you receive a survey in the post, please have your say. [@NHSEngland](#) [@PickerEurope](#)  
[#U16CancerPatientSurvey](#) [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk)

### Facebook

1. A childhood cancer diagnosis 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 to improve the care and support the NHS provides. The Under 16 Cancer Patient Experience Survey informs how we deliver cancer services for children and young people. If you receive a survey in the post, please take part. For more information, visit [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).  
[#U16CancerPatientSurvey](#) [#ChildrensCancer](#) [#ChildhoodCancer](#)
2. 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. To continue to improve our services, we want to listen and learn from the experiences of children diagnosed with cancer. If invited, have your voice heard by completing the Under 16 Cancer Patient Experience Survey. For more information, visit [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).  
[#U16CancerPatientSurvey](#) [#ChildrensCancer](#) [#ChildhoodCancer](#)
3. Help improve cancer services for young people and have your say. Children under the age of 16 cared or treated for cancer in 2023 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 receive a survey in the post, please have your say. [#U16CancerPatientSurvey](#)  
[www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk). [#U16CancerPatientSurvey](#) [#ChildrensCancer](#)  
[#ChildhoodCancer](#)

### Instagram stories

**Story one** - Childhood cancer 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** - The Under 16 Cancer Patient Experience Survey will inform how we deliver cancer services for children and young people. (Link to [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk))

**Story four** - If you receive a survey in the post, please have your say and help us improve our services. (Link to [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk))

### Instagram post

A childhood cancer diagnosis 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 to improve the care and support the NHS provides. The Under 16 Cancer Patient Experience Survey will help us understand and develop our cancer services for children and young people in line with their needs.

#U16CancerPatientSurvey #cancercare #childrenwithcancer

### LinkedIn

The Under 16 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 survey will 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 who received cancer-related care and treatment in 2023, and their parents or carers, will receive a survey in the post from April 2024. For more information, visit [www.under16cancerexperiencesurvey.co.uk](http://www.under16cancerexperiencesurvey.co.uk).

## 5) FAQs

For questions about the survey, please refer to the Under 16 Cancer Patient Experience Survey website: <https://www.under16cancerexperiencesurvey.co.uk/faq>