

National Patient Surveys Cancer Patient Experience Survey (CPES) and Quality of Life (QoL)

Every comment counts - help shape your NHS cancer services.

Below we have provided a summary of each of the national cancer surveys which take place every year. This information has been publicly sourced and condensed from NHS England to help you understand the purpose, and differences, of both surveys. For any queries in relation to each survey, we advise that you contact the support services found directly on each website which are linked below.







CPES AND U16CPES

What is it?

The National Cancer Patient Experience Survey (CPES) is a survey managed by NHS England (NHSE) as part of the national NHS Cancer Programme. The survey is designed to monitor national progress on cancer care, drive local quality improvements, and inform the work of charities/ groups supporting cancer patients. The survey runs every year and is overseen by a NCPES Advisory Group, who set the objectives of the survey and guide development of the questionnaire.

How does it work?

You will automatically be sent the survey if you are eligible. The survey is primarily paper-based and is sent by post. The letter also contains a link that you can use to complete the survey online. The survey is sent by an organisation called Picker – who run the survey on behalf of the NHS.

What happens to my answers?

Your answers are combined with everyone else who completes the survey to build up a national picture of people's experiences of cancer care services, and how they feel about the quality of cancer care that the NHS provides. The results are then published in a yearly report on the Cancer Patient Experience Survey website. Nobody will be able to identify you in any results that are published. Each cancer alliance can see a breakdown of where they compare in certain questions/results to the national average, and the report can also be broken down per hospital trust and tumour group/cancer type.

Why is it so important?

The survey helps to inform how and where the NHS should drive improvements into cancer services. The results will be looked at to understand differences in people's experiences, for example, to see if people answer differently depending on their ethnic group or type of cancer. This will help to identify where improvements are most needed and for which groups, communities, or populations. Because the survey is completed every year, it allows any changes to be tracked and monitored over time.

Who is it for?

CPES- This survey is for all adult patients (aged 16+) with a confirmed diagnosis of cancer, who have been admitted to hospitals as inpatients for cancer related treatment, or who were seen as day patients for cancer related treatment and have been discharged between April and June each year. This version of the survey has been in circulation since 2010, and generally runs between October-January, but this may differ from year to year. You can find out more from the <u>CPES website</u>, along with results of the survey from previous years.

U16CPES-The survey is for children under the age of 16 and their parents/carers who have recently has care at certain hospitals in England. There are three surveys given to different age groups:

- A survey for parents/carers of 0-7 year olds
- A survey for 8-11 year olds, with some questions for their parents/carers to complete
- A survey for 12-15 year olds, with some questions for their parents/carers to complete.





These versions of the survey have been in circulation since 2020, and generally run between April-June, but this may differ from year to year. You can find out more from the <u>U16CPES website</u>, along with results of the survey from previous years.

QoL

What is it?

The Cancer Quality of Life Survey (QoL) is a national survey managed by NHS England (NHSE) to find out how quality of life may have changed for people after being diagnosed with cancer. The survey helps to identify where care is working well/not so well, and if any new services are needed. Eighteen months on from a cancer diagnosis, patients rate their quality of life quite highly (74.2/100) but slightly below that of the general population (90.1/100). People diagnosed with stage 1 cancer report higher quality of life (76.5/100) than those diagnosed with stage 4 cancer (69.2/100). This further reinforces the NHS Long Term Plan to diagnose cancer earlier. The survey takes around 10 minutes to complete and asks about overall emotional, physical, and social wellbeing. It has been running since September 2020.

How does it work?

You will automatically be sent an initial invitation in the post to complete an online survey if you are eligible. You will also be sent a paper survey approximately 2 weeks after receiving the initial invitation. The survey asks people who have experienced cancer how they are feeling and compares answers with information about their diagnosis and treatment, in turn helping to improve the way that we support people to live as long and as well as possible. The survey is sent by an organisation called Quality Health – who run the survey on behalf of the NHS.

What happens to my answers?

Your answers are combined with everyone else who completes the survey and are used to build up a national picture on quality of life outcomes for people diagnosed with cancer. The results will be published in an online report, and nobody will be able to identify you in any results that are published. The report can be broken down per tumour group/cancer type and geographical area. Your answers will also be given back to you in a format that helps you to understand how your quality of life compares to other people in a position similar to you.

Why is it so important?

The information collected from the survey will help inform how the NHS can further support people living with and beyond cancer, to improve quality of life for cancer patients. The responses help NHSE to understand how quality of life differs depending on a person's age, gender, ethnicity, cancer type or stage at diagnosis. Because you can also access your individual summary report which shows how your quality of life compares to the general population, if any of your scores are not as expected, this may prompt you to access further support from your local health provider.

Who is it for?

The Quality of Life survey is for anyone who has been diagnosed with cancer and the survey invitation will be sent to them around 18 months after their diagnosis. You can find out more from the <u>Cancer</u> <u>Quality of Life Survey Website</u>, along with results of the survey from previous years.

