# Cancer Quality of Life Survey – Key Messages

This section provides text that can be used to communicate about the Cancer Quality of Life Survey accurately and consistently.

The section comprises:

* a brief paragraph capturing a high-level overview;
* long text to support written briefing papers;
* newsletter and website copy;
* and ‘bullet point’ messages.

The text can be selected, as required.

## Brief Copy

Quality of life means different things to different people, but it matters to everyone. More people are surviving cancer than ever before - but living with cancer, and the effects of its treatment, can have a negative impact on people’s physical, emotional and social wellbeing. Public Health England, NHS England and NHS Improvement understand that quality of life (QoL) outcomes are important to patients. We have launched a nationwide Cancer QoL Survey to help us understand what matters to patients. We are pleased to confirm that, from December, all patients diagnosed with breast, prostate or colorectal cancer in England will be invited to complete the survey 18-months after their diagnosis. People with other cancer types will be included from July 2021 onwards. The information collected from the survey will help us to work out how best to support people living with and beyond cancer. This is an ambitious programme with a scale and depth that isn’t being matched anywhere else in the world.

## Long Copy

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This is an ambitious programme with a scale and depth that isn’t being matched anywhere else in the world. Although patient reported outcome measures (PROMs) that focus on QoL are in use in parts of the NHS, and in clinical trials round the world, the potential for PROMs to improve care and outcomes for people affected by cancer has not yet been realised.

Only by monitoring QoL, using a consistent assessment point with nationwide coverage, can data be made available to help improve care across the NHS. For the first time, our survey will routinely measure QoL outcomes in a way that influences health policy, professional practice and patient empowerment.

We want to encourage as many people as possible to complete their survey so that the information collected fully represents our cancer population.

An experienced patient survey company (Quality Health) is managing the survey invite and response system. All the survey responses are being held securely by the Cancer Registry at Public Health England. The Cancer Registry are linking the survey responses with existing data related to each person’s diagnosis and treatment.

Eligible patients will receive a direct invitation to complete the QoL survey online. The survey is easy to complete and generally takes between five and 10 minutes. The survey asks about how people are doing. People’s answers can be related to their cancer diagnosis and treatment, other illnesses, or other things happening in their life. The survey company (Quality Health) is managing a website [www.CancerQoL.england.nhs.uk](http://www.CancerQoL.england.nhs.uk)and free helpline **0800 783 1775** to support patients to complete the survey and respond to any queries or difficulties.

The results will be analysed by Public Health England. We anticipate that national and regional level reports will start to be made available in the Autumn of 2021. We will also be testing the provision of individual summary reports to patients and their clinicians, prior to a decision on implementing these in 2021.

## Newsletter Copy

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To support the launch, xxxx Cancer Alliance is posting the question ‘what does quality of life mean to you?’ across social media channels to engage with our followers, directing people to the [website](http://www.cancerqol.england.nhs.uk/), utilising the case studies we’re creating or generate your own local ones, retweeting from personal/clinical accounts from across the Alliance, putting information on the Alliance/ICS website, raising awareness to all our partners and encouraging distribution of the core messages through all available channels.

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## Website Copy

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The results from the survey will be analysed and published by Public Health England. We anticipate that national and regional-level reports will start to be made available in the Autumn of 2021 through our public-facing website: <https://www.cancerdata.nhs.uk/>.

All researchers can make requests to obtain and analyse the anonymised dataset through requests to the Cancer Registry’s [Office for Data Release](https://www.gov.uk/government/publications/accessing-public-health-england-data/about-the-phe-odr-and-accessing-data). We will also be testing the use of individual summary reports that can be given directly to patients and their clinicians, prior to a decision on implementing these in 2021.

Information from the QoL survey will be used to understand where changes in care are needed. For example, depending on the results of the survey, we may want to improve psychosocial care that alleviates anxiety, or provide additional services to increase mobility, or target resources towards different patient groups or geographical areas that are at risk for poorer QoL outcomes.

Preliminary analyses from 2,703 people who completed the Survey during the 2018-19 pilots indicated that: QoL outcomes are likely to vary by stage of disease, cancer type, gender, age and levels of deprivation. Compared to a ‘general’ (non-cancer)

population, cancer patients may be more likely to report issues with anxiety and difficulty engaging in their ‘usual activities’ (for example, at work, when studying, around the house, during leisure activities or when doing things with their family).

## Bullet point key messages

### General

* Quality of life outcomes are important to people living with and beyond cancer.
* Measuring people’s quality of life increases our understanding of the impact of cancer and its treatment, and how well people are living after treatment.
* The Cancer Quality of Life Survey aims to measure quality of life at scale for people living with and beyond cancer.
* The NHS is committed to raising the profile of quality of life as part of its pledge to understand what matters to patients and ongoing work towards providing the best possible outcomes for everyone.

### About the Cancer Quality of Life Survey

* People will receive a survey invitation through the post 18 months after their diagnosis.
* People will initially be encouraged to complete the survey online. A paper-based option is also available.
* The survey takes between five and 10 minutes to complete.
* Patients will be asked to complete two widely used quality-of-life questionnaires: the generic EQ-5D and the cancer-specific EORTC QLQ-C30.
* Patients’ survey responses are being linked with data held about them in the Cancer Registry to provide an overview of whether quality of life differs, for example, depending on age, gender, cancer type or stage at diagnosis.
* A small-scale test of providing individual reports to patients and clinicians has proved successful; wider-scale tests of providing patients with a summary report containing their own QoL scores will start in 2021.
* There is a free helpline and website to support patients and staff with any questions about the survey.
* The survey is being carried out by a centrally-run survey company (Quality Health) under direction from Public Health England, NHS England and NHS Improvement.

### Pilot testing projects

* Pilot projects in 2018 and 2019 tested data collection methods and gathered data to develop summary QoL metric(s).
* Eight Trusts in five Cancer Alliances took part in the pilot.
* Patients taking part in the pilot project found the survey easy and acceptable to complete.
* The most recent independent evaluation report found an average survey response rate of 56%.

### Data reporting plans

* The results from the survey will be analysed and published by Public Health England.
* We anticipate that national and regional-level reports will start to be made available in the Autumn of 2021 through our public-facing website: <https://www.cancerdata.nhs.uk/>.
* All researchers can make requests to obtain and analyse the anonymised dataset through requests to the Cancer Registry’s [Office for Data Release](https://www.gov.uk/government/publications/accessing-public-health-england-data/about-the-phe-odr-and-accessing-data) .
* We will also be testing the use of individual summary reports that can be given directly to patients and their clinicians, prior to a decision on implementing these in 2021.
* Information from the QoL survey will be used to understand where changes in care are needed. For example, depending on the results of the survey, we may want to improve psychosocial care that alleviates anxiety, or provide additional services to increase mobility, or target resources towards different patient groups or geographical areas that are at risk for poorer QoL outcomes. Information from the survey could also be used to inform future treatment decisions, if it is shown that particular treatments are associated with better quality of life outcomes.
* Preliminary analyses from 2,703 people who completed the Survey during the 2018-19 pilots indicated that:
  + QoL outcomes are likely to vary by stage of disease, cancer type, gender, age and levels of deprivation.
  + Compared to a ‘general’ (non-cancer) population, cancer patients may be more likely to report issues with anxiety and difficulty engaging in their ‘usual activities’ (for example, at work, when studying, around the house, during leisure activities or when doing things with their family).

### What is happening now

* The Cancer Quality of Life Survey started sending out invites in September 2020 to a small group of patients. From December 2020 *all* breast, prostate and colorectal cancer patients will receive a survey invite 18-months after their diagnosis.
* All cancer types will be included in the survey from 2021 onwards. This includes rarer and less survivable cancers, such as brain and other CNS cancers.
* We are raising awareness of the survey in all primary, community and secondary care providers, and with commissioners.
* We want to encourage as many people to take part as possible so that the information collected fully represents our population.
* We will make sure that NHS staff who normally deal with cancer patients know how to respond to queries about the survey and know how to get additional information and support.
* Please contact [Erin.Barton@nhs.net](mailto:Erin.Barton@nhs.net) (or add your own contact details) if you have any questions about the survey – we are keen to help.
* Your Cancer Alliance and the NHS England Living with and Beyond Cancer team are fully briefed on how to support you.