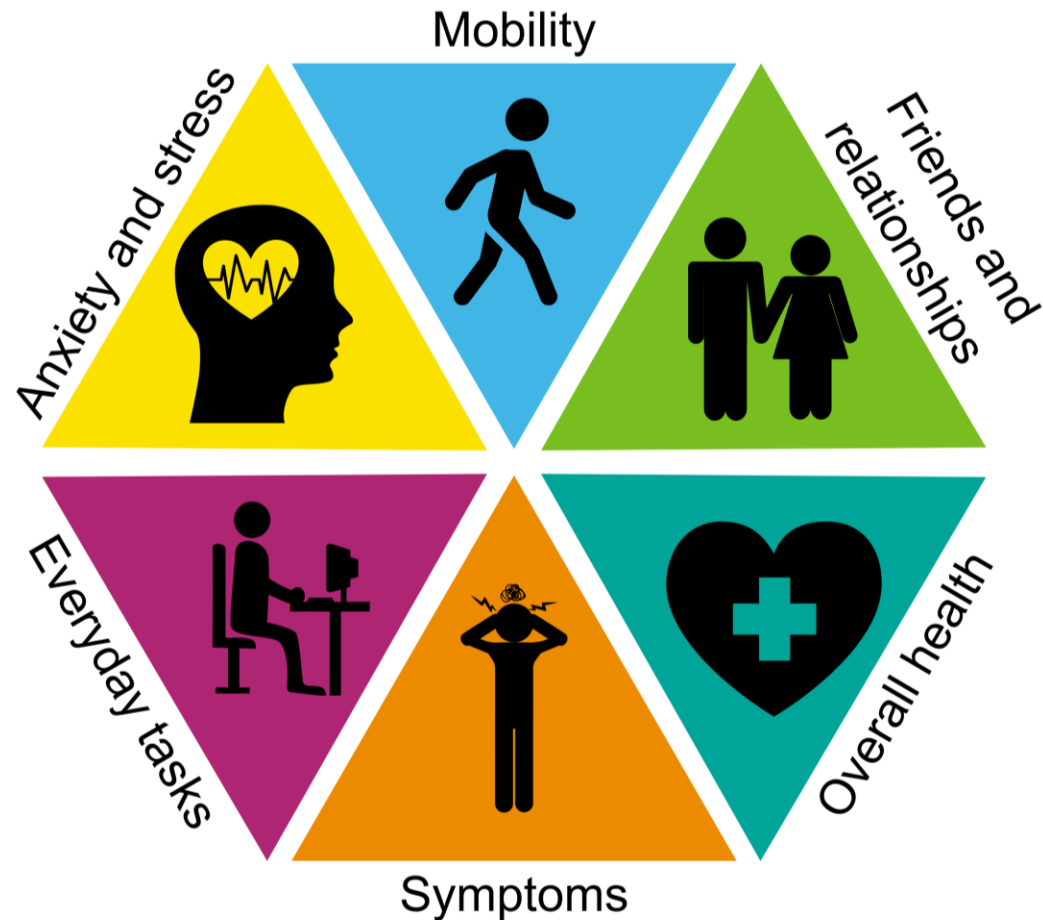


Quality of Life (QOL) Survey



Communications toolkit

This toolkit is designed to help promote the Quality of Life (QoL) survey in your area. This toolkit is a guide - communications will need to be adapted locally, to meet the needs of your audience. All resources can be found on the [NHS Futures workspace](#).

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KEY MESSAGES



A full set of key messages can be found on the [NHS Futures workspace](#).

Key messages for the launch of the first data

- National, Cancer Alliance and regional-level data will be available from the 25 October 2021 through the public-facing website: <https://www.cancerdata.nhs.uk/cancerqol>
- The first results include responses from people invited between September 2020 and July 2021.
- The results show that generally, 18 months on from a cancer diagnosis, patients rate their quality of life quite highly, 75.2/100, but slightly below that of the general population, 81.8/100. The NHS Cancer Programme is seeking to close that gap.
- The results demonstrate some variation between Cancer Alliances and different cancer types. We will be working with Cancer Alliances and clinicians to understand and address this.
- There are existing initiatives that can improve quality of life, such as:
 - Improving the delivery of personalised care and support planning.
 - Completing implementation of Personalised Stratified Follow Up.
 - Ensuring Cancer Care Reviews take place from diagnosis onwards.
- The Survey will also inform and establish future initiatives to improve long-term quality of life for people diagnosed with cancer both in the past and in the future.
- We will also be able to look at the data over time to monitor and target improvements.

Background information to support answering questions about the survey

General

- Quality of life is vitally important to people living with and beyond cancer.
- Measuring people's quality of life increases our understanding of the immediate and longer term impact cancer and its treatment has on patients.

- The Cancer Quality of Life Survey aims to measure quality of life at scale for people living with and beyond cancer in order to influence health policy, professional practice and patient empowerment.
- 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 around 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: EQ-5D and 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.
- Patients completing the survey can access their individual summary report which shows their quality of life scores with a comparison to the general population.
- There is a free helpline and website to support patients and staff with any questions about the survey.
- More information about the survey can be found at the survey website: www.cancerqol.england.nhs.uk.

ABOUT

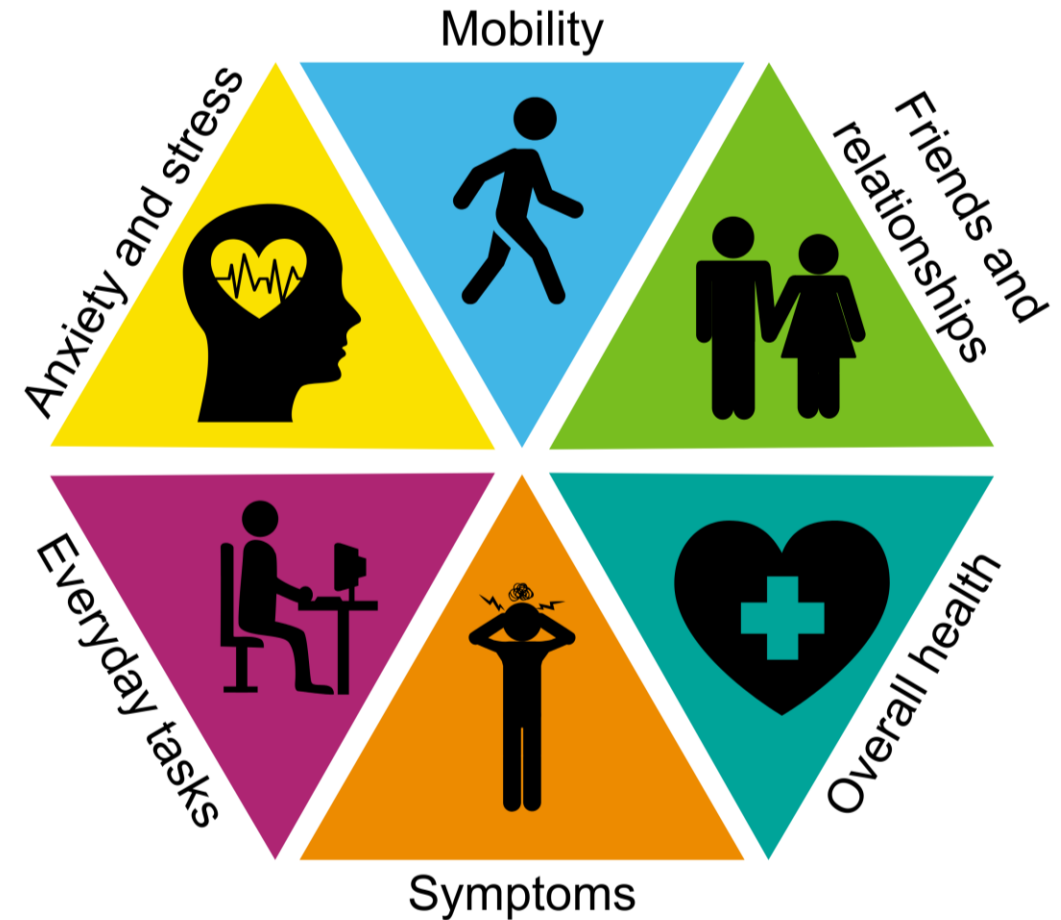


Brief Copy

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. NHS England and NHS Improvement and NHS Digital understand how important quality of life is and the difference it makes to patients. The Cancer Quality of Life (QoL) Survey help us understand what matters most to patients. The information collected from the survey will help us to work out how best to support people living with and beyond cancer. This is the first survey to routinely measure quality of life outcomes in a way that influences health policy, professional practice and patient empowerment nationally.

The survey was launched in September 2020 and has since been rolled out to all patients diagnosed with breast, prostate or colorectal cancer in England. From October 2021 all cancer patients will be invited to complete the survey. Patients receive the survey around 18-months after their diagnosis.

The [first results](#) of the survey show that although patients reported relatively high quality of life, it is still slightly lower than the general population. We are now looking at how we can close this gap.



ABOUT



Long 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. , NHS England and NHS Improvement and NHS Digital understand that quality of life outcomes are important to patients. We are running a nationwide Cancer Quality of Life (QoL) Survey to help us understand what matters to patients. The survey was launched in September 2020 and has since been rolled out to all patients diagnosed with breast, prostate or colorectal cancer in England, and has since been rolled out to all patients diagnosed with breast, prostate or colorectal cancer in England. From October 2021 all cancer patients will be invited to complete the survey. This includes rarer and less survivable cancers, such as brain and other CNS cancers. Patients receive the survey around 18 months after their diagnosis. 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. Although patient reported outcome measures (PROMs) that focus on quality of life are in use in parts of the NHS, and in clinical trials worldwide world, the potential for PROMs to improve care and outcomes for people affected by cancer has not yet been realised. Only by monitoring quality of life, at 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 quality of life outcomes in a way that influences health policy, professional practice and patient empowerment. It's important that as many patients as possible to complete their survey so that the information collected fully represents our cancer population.

More information about the survey can be found on the survey website: www.CancerQoL.england.nhs.uk. There is also a free helpline **0800 783 1775** to support patients to complete the survey and respond to any queries or difficulties.

Patients completing the survey can access their individual summary report that shows their quality of life scores with a comparison to the general population. The summaries can enable patients to have conversations about quality of life and access any further support required.

First results from the survey will be available at www.cancerdata.nhs.uk/cancerqol from end of October 2021. Data will be available in national, Cancer Alliance and regional breakdowns. The [first results](#) of the survey show that although patients reported relatively high quality of life, it is still slightly lower than the general population. We are now looking at how we can close this gap.

WEBSITE 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. NHS England and NHS Improvement and NHS Digital have launched a nationwide Cancer Quality of Life Survey (QoL) to help us understand what matters to patients. The survey was launched in September 2020 for a small pilot of breast, prostate and colorectal cancer patients, and has since been rolled out to all patients diagnosed with breast, prostate or colorectal cancer in England around 18-months after their diagnosis. All cancer patients will be invited to complete the survey from October 2021. 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. Although patient reported outcome measures (PROMs) that focus on quality of life 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 quality of life, 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 quality of life 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.

More information about the survey can be found on the survey website:

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.

Patients completing the survey can access their individual summary report which shows their quality of life scores with a comparison to the general population.

First results from the survey will be available on a public-facing website (www.cancerdata.nhs.uk/cancerqol) from the end of October 2021. Data will be available at National, Cancer Alliance and Regional level.

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 quality of life outcomes.

The [first results](#) of the survey show that although patients reported relatively high quality of life, it is still slightly lower than the general population. We are looking at how we can close this gap.

The results demonstrate some variation between Cancer Alliances and different cancer types and can enable local systems to act on the data as appropriate.

VISUAL IDENTITY



Full visual guidelines and resources for the QoL survey can be found on the [Future NHS workspace](#).

Primary logo - colourful hexagon, icons, labels

Where clear representation is needed, and a large amount of space is available so text is large enough to read e.g. posters, presentations and front covers

Secondary logo - colourful hexagon and icons only

To support key messages where display space is more restricted e.g. as part of webpage, report or letter text

Supporting logo - colourful hexagon only

To support key messages where space is limited e.g. social media, report footers and presentation master slides



Promote uptake of the survey in patients e.g. mentioning it in existing communications

Raise awareness of the survey in trusts and primary care e.g. through use of posters/flyers, or delivery of awareness raising activities

Encourage engagement with the current approach to QoL locally e.g. sharing best practice and identifying opportunities to start local quality improvement projects

Support patients to complete the survey and respond to queries e.g. in letters, emails or on social media, and escalating questions to the national team

SOCIAL MEDIA CONTENT



The below social media posts provide a guide on the type of content which can be used to raise awareness of QOL across your social media channels. Targeted ads can be used to ensure the content is reaching the right people. If you would like support or guidance on targeted ads please contact england.cancercomms@nhs.net.

Please use the following hashtags when posting on social media:

[#CancerQualityOfLife](#)

Secondary hashtags are also available:

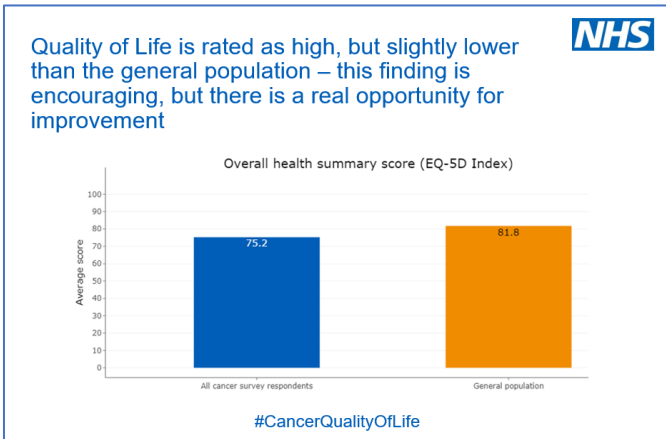
[#LivingWithAndBeyondCancer](#)
[#PersonalisedCare](#)

Example posts:

NHS England and NHS Improvement and NHS Digital are leading the way in cancer care by recognising that quality of life outcomes are as important to patients as survival. They are running a nationwide [#CancerQualityOfLife](#) survey. The information collected from the survey will be used to work out how best to support the growing number of people [#LivingWithAndBeyondCancer](#). The [first results](#) of the survey show that although patients reported relatively high quality of life, it is still slightly lower than the general population. We are looking at how we can close this gap. This is an ambitious programme with a scale and depth that isn't being matched anywhere else in the world. To find out more: www.CancerQoL.england.nhs.uk

Full social media assets can be found on the [Future NHS workspace](#).

SOCIAL MEDIA CONTENT - ASSETS



Why quality of life data matters

NHS

#CancerQualityOfLife

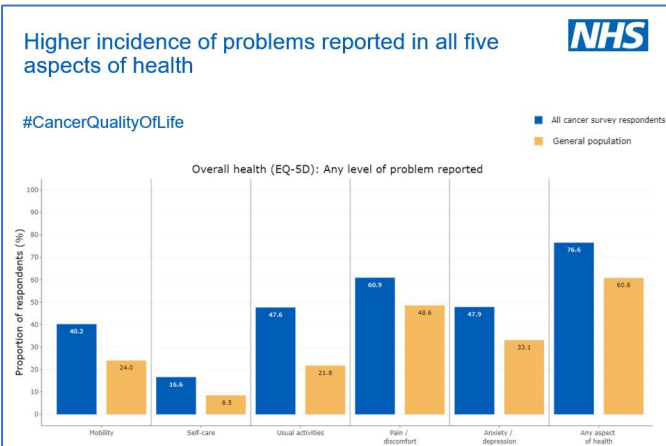
"I want to celebrate that the NHS is measuring quality of life for cancer patients at a scale and depth not being matched anywhere else in the world.

This powerful and informative data will help shape future services, but more importantly it empowers us to have meaningful discussions about our cancer journey."

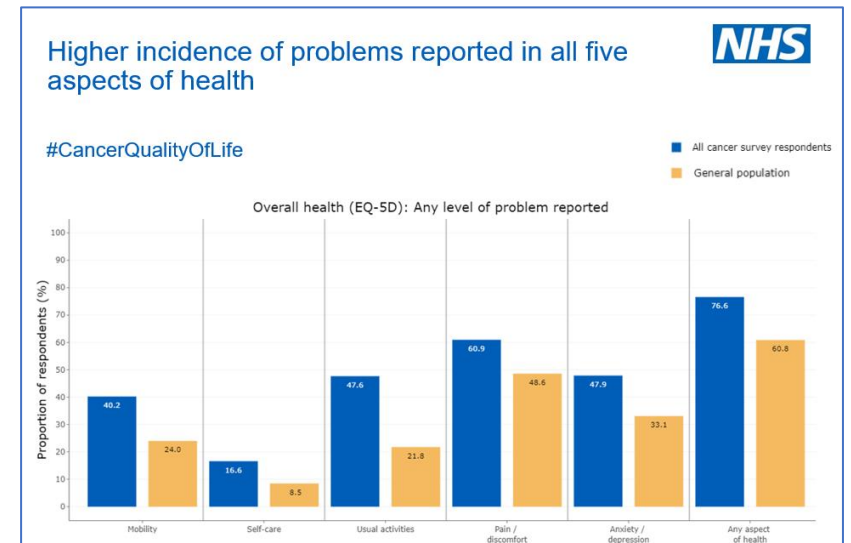
Juliette Chan – Patient and Public Voice Representative – Cancer Quality of Life Survey Steering Group

These images can be shared along with the social media messages about the first results of the survey. For example you could post:

@NHSEngland and @NHSDigital
 #CancerQualityOfLife survey measures the long term impact of cancer to a scale and depth that isn't being matched anywhere else in the world. [Find out more](#) today.



All social media assets are available in the [social media guide](#) and saved as images on the [Future NHS workspace](#).



SOCIAL MEDIA CONTENT



This twitter banner can be downloaded from Futures [here](#) to be used to promote the survey.



Tell us, how are you doing?

Please fill in the Cancer Quality of Life Survey if you're asked



There are also two videos that can be shared:

[What does quality of life mean to you?](#)

[Why is the survey important?](#)

POSTERS, SLIDES AND PRINTED RESOURCES



This poster is designed to explain the purpose and process of QoL.

The file can be downloaded from the Future NHS Workspace [here](#).



Tell us: how are you doing?

We know that people with an experience of cancer can have a range of problems from diagnosis to beyond their treatment.

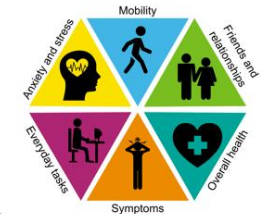
If you have had cancer, we may ask you to complete a Quality of Life Survey to look at your long-term health and wellbeing. We would like to learn more about problems you face so that we can understand how best to support people with cancer.

For more information please talk to your clinical team.



Cancer Quality of Life Survey

[#CancerQualityOfLife](#)
[#LivingWithAndBeyondCancer](#)
[#PersonalisedCare](#)



NHS England and NHS Improvement

The [QOL survey slide set](#) can be found on the workspace, along with the generic [slide template](#). These can be used as templates for presentations.



Thank You

For any questions, please contact england.cancercomms@nhs.net