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Cancer quality of life survey

Summary report: first data release October 2021

Version 1, 26 October 2021

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Foreword

The Cancer Quality of Life Survey in England was originally developed in response to an Independent Cancer Taskforce report to introduce an innovative quality of life metric to track and respond to the long-term impact of cancer. After piloting and refining the data collection, working closely with cancer charities and patient representatives, we are delighted to be able to share the initial results from the first survey of its kind in the NHS.

More people are surviving cancer than ever before. But we know that the long-term impact can be significant. As the results in this report show, people who have had a cancer diagnosis report a wide range of issues, including mobility, anxiety and mental health problems, and challenges just completing their usual daily activities. The results underline the importance of better understanding the challenges people living with and beyond cancer face, so that the NHS can constantly improve the support we are able to offer to our patients.

There are many actions the NHS can already take to ensure patients receive the right support – from ensuring every patient is offered a holistic needs assessment to inform the comprehensive care and support they require, to implementation of more personalised follow-up arrangements, enabling patients to take control of their follow-up and ensure they can access support when they need it. Work is already under way to better signpost and improve access to mental health support and psychological therapies (such as improving access to psychological therapies [IAPT] and charity services) for those with a cancer diagnosis who need it.

But we know that to close the gap in quality of life between those who have had a cancer diagnosis and the general population, more will be required. This first publication is the beginning of a process, starting with better understanding of patients' needs, and leading to better care, greater personalisation, and the modernisation of the support we offer to people following a cancer diagnosis.



Dame Cally Palmer
National Cancer Director



Professor Peter Johnson
National Clinical Director
for Cancer



Lynda Thomas
Chair of the NHS Cancer
Programme Charity Forum

“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

1. Executive summary

The national Cancer Quality of Life survey in England was launched in September 2020 in response to the NHS Long Term Plan commitment to introduce an innovative quality of life (QoL) metric to track and respond to the long-term impact of cancer. This report includes the results of the initial phase of rollout, focused on those with a diagnosis of breast, prostate or colorectal cancer.

The survey includes questions from two well-known and well-tested quality of life questionnaires called EQ-5D-5L and EORTC QLQ-C30. EQ-5D-5L is a general survey used in many patient groups, while EORTC QLQ-C30 is used only in people with experience of cancer.

Between September 2020 and July 2021, 66,569 invitations were sent, and 34,387 surveys completed; the response rate for the survey is 51.7%.

Key findings

1. Eighteen months on from a cancer diagnosis, patients rate their quality of life quite highly (75.2/100), but slightly lower than the general population (81.8/100). People living with and beyond cancer are significantly more likely to report a problem across all five aspects of health (mobility, self-care, usual activities, pain and discomfort, and anxiety and depression) than the general population. These differences are particularly marked for ‘usual activities’ (such as work, study, housework, family or leisure activities) and mobility.
2. Mental health is a priority. In our survey, cancer patients are 1.5 times as likely to report a problem with anxiety and depression than the general population.

3. Most of the difference between people living with and beyond cancer and the general population is due to higher levels of slight to moderate problems; the most severe level is not more common in the cancer survey respondents.
4. Some patients continue to experience symptoms and side-effects at a level that might benefit from further investigation from health care professions. Most common in this sample are difficulty sleeping (26.6%), fatigue (13.4%), and constipation (9.6%).

The results of the survey reinforce the importance of existing interventions that provide support to people living with and beyond cancer, including the implementation of personalised care interventions and personalised stratified follow-up pathways.

Following the publication of these new data, NHS England and NHS Improvement will continue to publish the data publicly, and to work with stakeholder organisations, researchers and clinicians to develop and implement interventions to address the quality of life issues that people raise through the survey.

2. Background

The national Cancer Quality of Life survey in England was launched in response to the NHS Long Term Plan commitment to introduce an innovative Quality of Life metric to track and respond to the long-term impact of cancer.

After a process of piloting and refining the methodology, the survey was launched in September 2020 to people with a diagnosis of breast, colorectal or prostate cancer. People are invited to participate 18 months after receiving a cancer diagnosis. From July 2021, 10% of people with other cancer types have been invited 18 months post diagnosis, with this expanding to all people with a diagnosis of cancer from October 2021. Once fully rolled out, over 200,000 people each year will be invited to complete the survey.

The Cancer Quality of Life Survey is world leading, routinely measuring Quality of Life outcomes to help improve care and outcomes for people diagnosed with cancer.

The first findings from the survey were published in October 2021 and mark the first step towards a richer understanding of long-term Quality of Life for people following a cancer diagnosis, which will in turn help us to build on our current work to improve services.

3. About the survey

The survey includes questions from two well-known and well-tested quality of life questionnaires called [EQ-5D-5L](#) and [EORTC QLQ-C30](#).

[EQ-5D-5L](#) can be used in any patient group and the general population. It has five items asking about mobility, self-care, usual activities (such as work, study, housework, family or leisure activities), pain and discomfort, and anxiety and depression.

Each of the items can be reported individually or a summary score calculated, called the EQ-5D Index.

[EORTC QLQ-C30](#) is a cancer-specific questionnaire, suitable for use with all cancers. It has 30 items. These are used to produce summary scores for different functional categories: physical, social, emotional, role function, such as work and leisure and cognitive function.

The questions also include some of the more common symptoms and side effects, such as pain and fatigue, which are reported separately.

For more detail about the survey please visit the website:

www.cancerqol.england.nhs.uk

4. Key findings

These first findings report responses from 34,387 people with a diagnosis of breast, colorectal or prostate cancer, approximately 18 months from diagnosis.

4.1 Key finding 1

Eighteen months on from a cancer diagnosis, patients rate their quality of life quite highly, but slightly lower than the general population (Table1, Fig 1 below).

Table 1: EQ-5D Index mean score and confidence intervals*

Cancer survey respondents: average score (95% CI) 75.2 (75.0-75.5)	General population: average score (95% CI) 81.8 (81.3-82.3)
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*These scores are not adjusted for age or sex

Figure 1: Overall health summary score (EQ-5D Index)

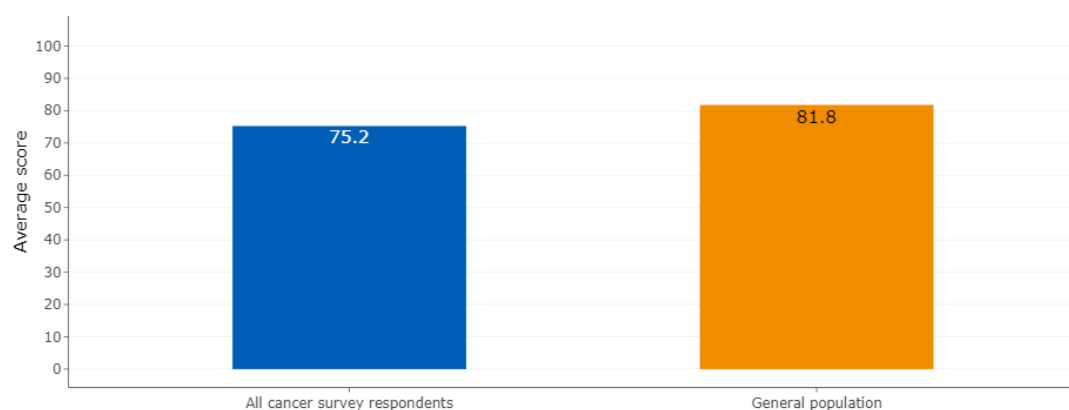


Fig 1 shows a summary score from the questionnaire measuring overall health (EQ-5D). It is based on how the person answers each of the five individual questions that make up the questionnaire. The maximum score is 100; higher scores suggest better quality of life. The data for cancer survey respondents are not adjusted for age or sex.

This finding is encouraging, suggesting that most people are experiencing a relatively good quality of life 18 months after diagnosis. However, it also represents a real opportunity for improvement – there is a real and statistically significant gap between those with a cancer diagnosis and the general population, and other data from the survey demonstrate that respondents do struggle with a wide range of quality of life issues.

4.2 Key finding 2

The EQ-5D questionnaires measures mobility, self-care, usual activities, pain and discomfort, and anxiety and depression.

People living with and beyond cancer are significantly more likely to report a problem across all five aspects of health than the general population (Fig 2).

These differences are particularly marked for ‘usual activities’ (such as work, study, housework, family, or leisure activities) and mobility.

Mental health is a priority for the NHS Cancer Programme. In our survey, cancer patients are nearly 1.5 times as likely to report a problem with anxiety and depression than the general population. It is essential that people know about and can access appropriate support for their mental health from diagnosis onwards. In 2021, a task and finish group has developed recommendations for recovery of cancer psychosocial support following the pandemic. A key part of this is for the NHS Cancer Programme to seek consensus from stakeholders on a joint statement on what excellent psychosocial care in cancer looks like, and produce a toolkit of resources which will support implementation of the full set of recommendations.

Figure 2: Overall health (EQ-5D) any level of problem reported

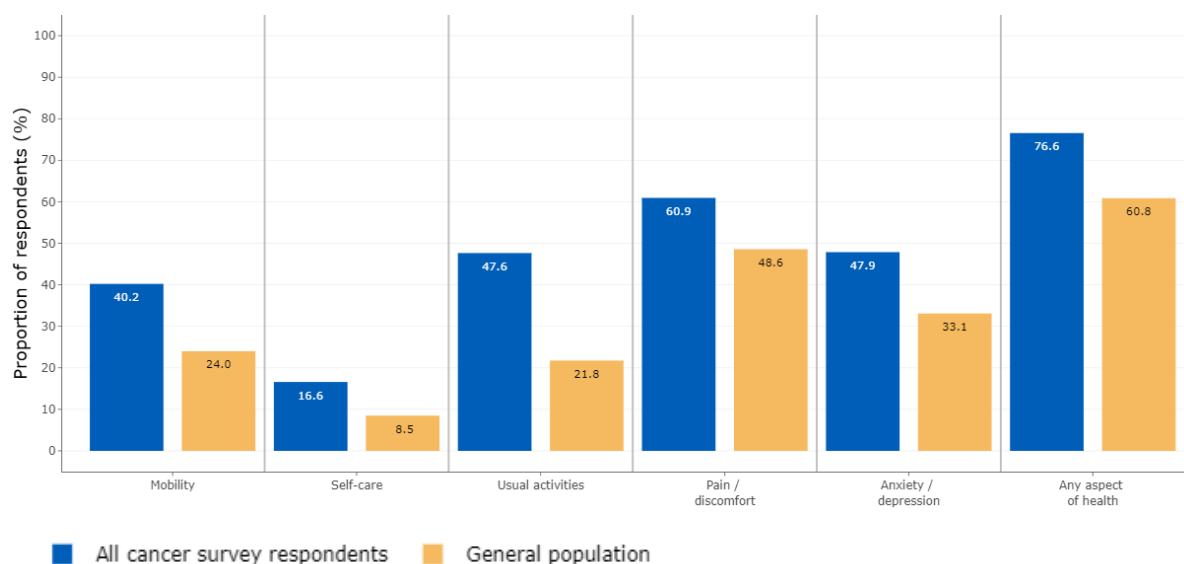


Fig 2 shows the percentage of people who reported any level of problem (slight/moderate or severe/unable) on each aspect of health. The higher the bar, the more people in each group reported a problem. The data for cancer survey respondents are not adjusted for age or sex.

4.3 Key finding 3

Most of the difference between the proportion of people with a cancer diagnosis reporting quality of life issues and the general population is explained by high levels of people with a cancer diagnosis reporting ‘slight to moderate’ severity problems (Fig 3). However, there are areas which require further investigation – for example,

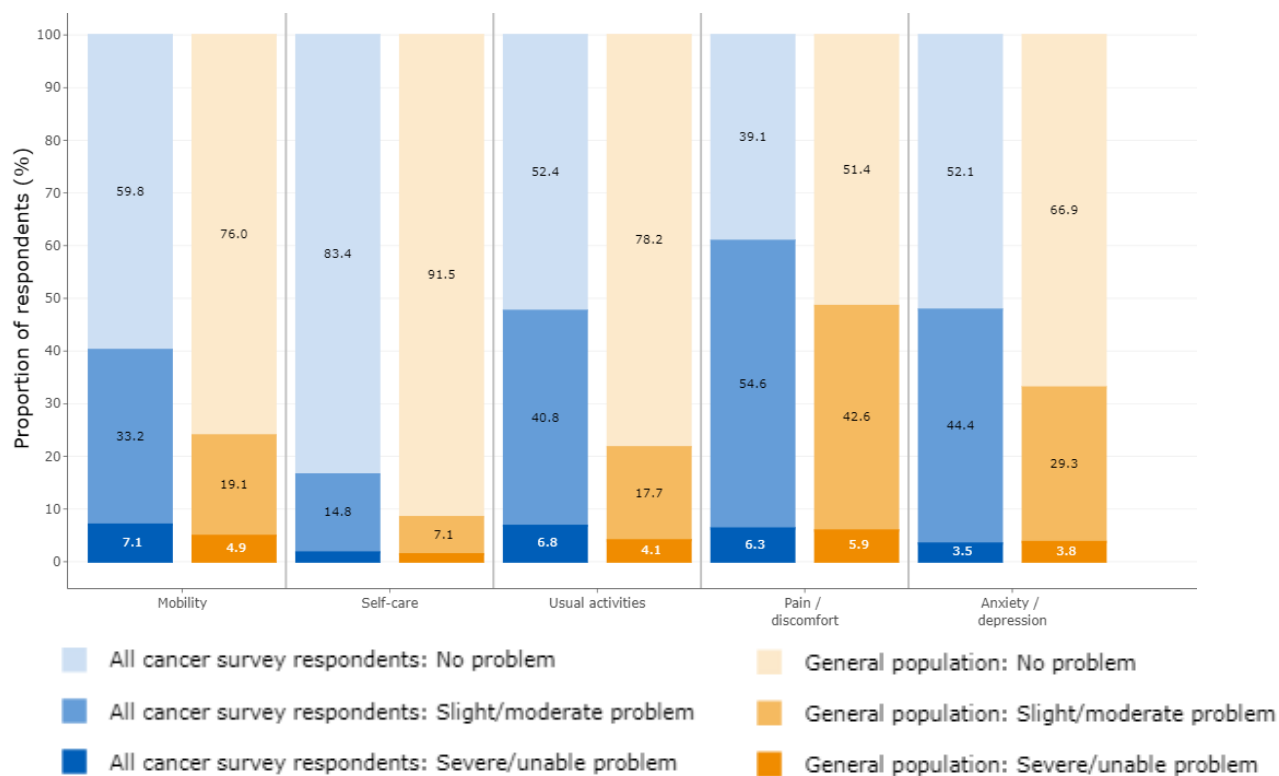
although the overall numbers are relatively low (7.1%), nearly 50% more people with a previous cancer diagnosis report ‘severe’ mobility problems relative to the general population (4.9%), with a further 33.2% reporting slight to moderate issues, compared to 19.1% in the general population.

Similarly, for those reporting issues with ‘usual activities’, although the overall numbers are fairly low (6.8%), over 50% more people living with and beyond cancer report a severe problem than the general population (4.1%). A further gap of 40.8% to 17.7% remains for slight to moderate problems.

By contrast, the gaps between those with a cancer diagnosis and the general population in self-care, pain/discomfort and anxiety/depression are entirely comprised of slight to moderate problems, although those gaps are still quite large.

Fig 3 looks at the severity of problem reported on each aspect of health. It shows the percentage of people who reported each level of problem on each aspect of health. The data for cancer survey respondents are not adjusted for age or sex.

Figure 3: Overall health (EQ-5D) severity of problem reported

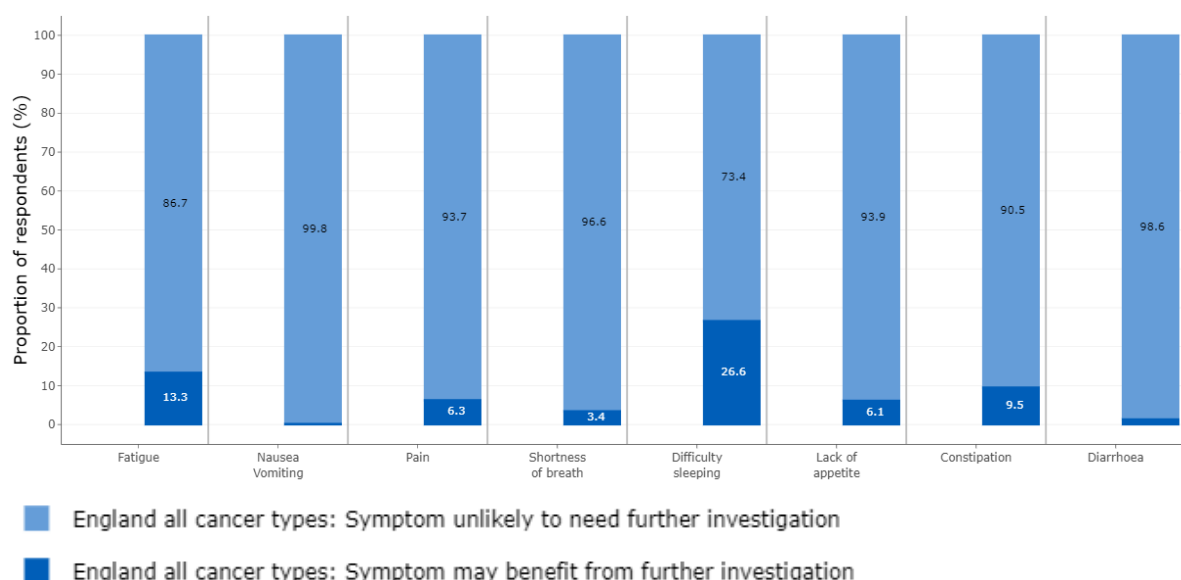


4.4 Key finding 4

Eighteen months on from diagnosis, some people continue to experience symptoms and side-effects at a level that might benefit from support for self-management and/or further investigation from health care professionals (Fig 4). Most common in this sample are difficulty sleeping (26.6% of people), fatigue (13.3%), and constipation (9.5).

Fig 4 shows how people responded to questions about the symptoms they are experiencing. It shows the percentage of people who report each symptom at a level that might benefit from further investigation.

Figure 4: Quality of life symptom scores (EORTC QLQ-C30)



Personalised care interventions, such as personalised care and support planning based on holistic needs assessment, can help to identify people's concerns at different points in their cancer pathway and enable signposting or referral, as appropriate, to sources of health and wellbeing advice, information, support and care to support them with managing ongoing symptoms like this.

The end of treatment summary is personalised for an individual, and describes potential longer-lasting or late-presenting problems after treatment has ended; this can guide people to self-manage as appropriate (for example with physical activity or dietary changes) and also to know how to seek help when needed.

Cancer care reviews in primary care are now being rolled out so they are offered twice in the first 12 months after diagnosis; the review provides an opportunity for the primary care team to provide direct support as appropriate (eg social prescribing), and also utilise preventative interventions.

At the point of the survey, most people will be in follow up – and with personalised stratified follow-up being rolled out, this is providing people with more education on self-management along with rapid access back to the cancer team for any concerns. It is key that people feel empowered to report problems that arise; the QoL survey patient summary is another tool that is designed to assist this.

4.5 Data dashboard

All the data in this report have been published on a publicly available dashboard, which can be seen at: www.cancerdata.nhs.uk/cancerqol. The dashboard can be used to explore findings from 23 different metrics from the two questionnaires which can be compared at a national level, filtered by geographical area (cancer alliance or NHS region) and/or cancer type, and comparisons can be made by age and sex.

The dashboard at its launch on 25 October 2021 includes data from 34,387 people with breast, prostate or colorectal cancer who completed the survey around 18 months after diagnosis.

It includes responses from people invited to complete the survey between September 2020 and July 2021. The next planned update of the dashboard is in April 2022. This will include responses from people with all cancer types. The dashboard will be updated every six months.

5. Who has taken part in the survey so far?

Between September 2020 and July 2021, 66,569 invitations were sent, and 34,387 surveys completed. This means the response rate for the survey is 51.7%.

The table below shows number of respondents and response rate for different groups of people invited to the survey.

The column 'number of respondents' shows the percentage of invited people within that group who responded.

For example, 13,076 people with breast cancer have completed the survey. This is 49.3% of all people with breast cancer that have been invited to take part.

		Number of respondents	Response rate
Total overall		34,387	51.7%
Cancer type	Breast	13,076	49.3%
	Colorectal	7,307	51.4%
	Prostate	14,004	55.0%
Ethnic group	White	29,037	53.8%
	Black	451	29.4%
	Asian	549	28.9%
	Mixed	107	30.9%
	Other	3,877	50.7%
	Unknown	366	48.7%
Sex	Male	18,282	54.2%
	Female	16,105	49.6%
Age group	<50	2,403	40.0%
	50-59	5,313	46.1%
	60-69	10,510	55.7%
	70-79	11,890	58.6%
	80+	4,271	44.8%

Overall, response rates have been above or around the target level, with over 50% of all those invited responding. However, there are some notable exceptions, with much lower response rates from ethnic minority invitees in particular. Over the coming months, work to encourage improved response rates from ethnic minority invitees and younger people will be essential to ensure a truly representative survey.

6. Next steps

This is an important moment for people living with and beyond cancer and those who support, treat and care for them – quality of life really matters. The QoL survey and its work will be guided by key priorities: increasing participation in the survey particularly in underrepresented groups, piloting for the inclusion of different cancer types, disseminating the findings widely to different audiences, and sharing the data.

We know there is much that can already be done to improve the lives of those living with the impact of cancer and its treatment. For example, through improved delivery of personalised care and support planning, completing implementation of personalised stratified follow-up and ensuring cancer care reviews take place from diagnosis onwards. However, there are disparities in QoL that need to be better identified and more comprehensively addressed.

We are committed to ensure the data from the survey informs future policy and decision-making to improve long-term quality of life for people diagnosed with cancer both in the past and in the future. We will engage with a wide range of stakeholders to discuss how best to use the data to make the most impact on people's quality of life.

Following initial publication of the data, we will build on this momentum by bringing together key experts and stakeholder groups to identify the areas indicated for action by the results and begin to develop proposals to improve outcomes.

We plan to hold eight initial focus group sessions with regional NHS teams, cancer alliance teams, researchers and people/organisations representing the breast, colorectal and prostate cancer communities. This will lead on to more extensive engagement in 2022 and beyond.

We will continue to work closely with key partners including Macmillan Cancer Support and other cancer charities who have been instrumental to the success of this programme.

The publishing of the dashboard is just the beginning. By tracking the data over time, we will be able to monitor and target improvements in quality of life for those living with the impact of cancer and its treatment.

Please explore the data for yourself: www.cancerdata.nhs.uk/cancerqol