Cancer Research UK Cancer Patient Experience Survey 2020

The impact of COVID-19 on cancer patients in the UK

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The impact of COVID-19 on cancer patients in the UK

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Lastly, thanks to the Media Volunteer Liaison team for co-ordinating the case studies presented alongside the data in the following report.

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1 Executive summary

Overall for many cancer patients the COVID-19 pandemic appears to have had a significant impact on their testing and treatment, and most notably their care:

- 2 in 5 cancer patients surveyed reported that their testing had been impacted.
- 1 in 3 cancer patients surveyed reported that their treatment had been impacted.
- 2 in 3 cancer patients reported that their cancer care had been impacted.
- Ratings of overall cancer care as 'very good' decreased from 75% 'before lockdown started' to 37% 'after lockdown started'.
- Possible significant differences in experience were found by region in England for testing, treatment and care ($p < .01$).
- Possible significant[1] differences in experience for care was flagged for social economic status (SES), nation, region and cancer type ($p < .01$).
- 71% of cancer patients stated that they had been treated in the same hospital as usual, with no significant differences by SES, cancer type, nation or region.

This has resulted in a negative impact on the emotional well-being of many cancer patients:

- The most common emotions reported were 'anxious' and 'frustrated'. This was consistent for all patients surveyed, those who reported to have their testing and treatment impacted, and across breakdowns (SES, nation region and cancer type).
- 'Catching COVID-19' and 'becoming seriously ill from COVID-19' were the most selected concerns, and there was a lot of frustration reported in the open text comments regarding the feeling that COVID-19 patients are being prioritised over cancer patients.

The government actions that yielded the strongest support during the COVID-19 pandemic were those that would continue to allow testing and treatment to go ahead safely. The actions most supported after the COVID-19 pandemic were ones that would ensure capacity could be met and the backlog of cancer patients addressed:

- 88% of cancer patients surveyed felt the government should 'offer a safe environment, such as a COVID-19 free zone, for cancer patients to be treated' during the pandemic.
- 86% of cancer patents surveyed felt the government should 'ensure NHS staff have adequate access to Personal Protection Equipment (PPE)' during the pandemic.
- 84% of cancer patients felt the government should 'ensure NHS staff and cancer patients are regularly tested for COVID-19 regardless of if they have symptoms' during the pandemic.
- 92% of cancer patients surveyed felt the government should 'reinstate cancer screening programmes as quickly as possible' after the COVID-19 pandemic.
- 85% of cancer patients survey felt the government should ensure 'treatment services return to pre COVID-19 levels as quickly as possible' after the pandemic.

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1 1% significance level was reported ($p < .01$) the Bonferroni adjusted threshold is $p < .000125$. Where $p < .01$ but $p > .000125$ significant differences are possible, however statistical power is weakened due to the number of comparisons; where $p < .000125$ we can say is significant to stronger degree of certainty.

2 Introduction and methods

2.1 Background

A pneumonia of unknown cause was first detected in Wuhan, China on 31 December 2019. A global pandemic of the SARS-COV-2 virus, more commonly referred to as COVID-19 or the coronavirus, was declared by the World Health Organisation (WHO) 11 March 2020. Since this declaration the United Kingdom (UK), following several other countries worldwide, went into lockdown on 23 March 2020. As of 1 April 2020, more than 800,000 cases of COVID-19 were confirmed worldwide (WHO, 1 April 2020). There were international concerns of the impact of COVID-19 on health care systems, and the UK's main early COVID-19 message was: 'stay home, protect the NHS, save lives'.

Cancer is the leading cause of death in the UK, and cancer doesn't just stop because of a pandemic. Before COVID-19 there were around 367,000 new cases of cancer in the UK, and sadly, around 165,000 deaths (CRUK, July 2020). Early diagnosis followed by swift access to the most effective treatment remains as important as ever for survival. It is also essential to preserve cancer patients' quality of life through a personalised, holistic approach to their care.

Over 2 million people were estimated to be waiting for cancer screening, testing and treatments (CRUK, June 2020). In addition to this, many cancer patients may have been asked to shield, causing immediate disruption to daily life including not being able to see family and friends or do food shopping.

In response to this crisis, Cancer Research UK (CRUK) conducted a survey[2] aiming to understand the impact of COVID-19 on cancer patients' testing, treatment and care, day-to-day lives and wellbeing, and support for government policies.

2.2 Participants

1,868 cancer patients (average age 60; the youngest cancer patient was aged 13 and the oldest was 91) took part in this survey (see **Table 1** and **Table 2**). Those who stated they were from outside of the UK or selected that they 'were not a cancer patient' were excluded from further analysis (n = 26). Remaining cancer patients (N=1,842) were weighted[3],[4] to be representative of the UK by geography (nation and region), estimated social status[5], and gender. As part of the survey, cancer patients were asked if they would be happy to be contacted to take part in further research. Those who gave consent to be contacted again, were followed up, and a small sample (n = 6) provided case studies, which are presented alongside the results in this report.

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2 For a copy of the survey please contact the author Charlotte Ide – charlotte.ide@cancer.org.uk

3 Nation region and gender were weigted to be representative of the UK by Geography and SES using https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland (ONS data)

4 Estimated social economic status was weighted based on: http://www.nrs.co.uk/nrs-print/lifestyle-and-classification-data/social-grade/ (NRS)

5 Social economic status or level of deprivation was measured using the National Readership Survey (grouped to two groups, one more and one less deprived, more commonly referred to as ABC1 and C2DE).

Table 1: Proportion of cancer patients with each cancer type

Cancer type	Weighted proportion
Breast	21.4%
Genitourinary (including bladder, kidney, prostate, testicular)	19.5%
Blood (including leukemia, lymphoma, Hodgkin and non-Hodgkin lymphoma, multiple myeloma)	15.7%
Gastrointestinal (including colon, rectal, anal, stomach, intestinal, oesophageal)	10.9%
Multiple selections made	9.2%
Gynaecological (including uterine, cervical, ovarian, vaginal, vulvar)	6.1%
Lung	4.6%
Head or neck (including mouth, throat, tongue, nasal)	3.9%
Skin cancer (melanoma and non-melanoma)	3.8%
Hepatobiliary (including pancreas, liver, biliary)	1.9%
Central nervous system, brain, eye	1.0%
Sarcoma (including soft tissue, osteosarcoma)	0.8%
Endocrine	0.6%
I don't know	0.4%
Prefer not to say	0.2%

Table 2: Proportion of cancer patients at each stage of cancer from 1 to 4

Stage number	Weighted proportion
Stage 1	23.7%
Stage 2	26.2%
Stage 3	22.3%
Stage 4	27.9%

2.3 Procedure

The survey collected data from 1st to 28th May and used opportunistic and snow ball sampling methods to recruit cancer patients. Methods to promote participation included: social media posts on the CRUK Twitter, Facebook and Instagram accounts, supporter emails, the CRUK Patient Involvement Network and CRUK Cancer Chat. We also requested that people share the survey with their networks and with other cancer patients to increase sample size and diversity. Participants did not receive any incentives for taking part in the survey. All questions were answered to the best of the cancer patients knowledge at the time.

After the survey closed, a small sample of cancer patients (who had consented to be re-contacted and provided contact details) were randomly selected to provide more in-depth case studies.

2.4 Analysis

Quantitative analysis: Descriptive findings from the survey were generated, and where statistical testing was conducted, Fisher's Exact Test or Chi square analysis[6] was used to test for differences between groups to identify any differences in experiences by SES, nation, region or cancer type.

Qualitative analysis: The qualitative survey entries were analysed using narrative analysis to code and generate key themes.

6 1% significance level, p <.01 indicates a possibly significant result, applying a Bonferroni adjustment for multiple comparisons p <.000125 for significant result. The Fisher test was used where an expected frequency was either below 1 or more than 20% of the expected frequencies were below 5. Fisher test simulated p value was used in these comparisons.

3 Impact on cancer services

This section covers the self-reported impact of COVID-19 on cancer patients' testing, treatment, and care.

Participants were asked if they had 'experienced any of the following since the start of lockdown' regarding their testing, treatment and care, and were provided with a list of options that included 'other'. The 'other' open responses for questions on testing and treatment yielded rich data, so were coded and quantified. A composite variable[7] was then created to group all those who stated they were impacted in at least one way. Anyone who selected 'not applicable' to the following questions on testing, treatment or care were excluded from analysis, in addition to the exclusions mentioned in 'Introduction and Methods' (p5).

3.1 Impact on testing

In this report testing is defined as a wide range of testing, from scans to blood tests and screening where mentioned. Where testing is reported as impacted, this meant that cancer patients reported that the testing they would usually expect was delayed, cancelled and/or that they experienced different testing to what they had expected or planned.

46% of cancer patients surveyed reported that their testing continued as expected, while 42% of cancer patients reported they had been impacted in at least one way. Here are some examples of how cancer patients' testing had been impacted:

> "Concerned that a test to check on whether tumour has returned is not going ahead." – **Male aged 69 with stage 2 genitourinary cancer**

> "My annual mammogram is postponed indefinitely. I don't understand why that's considered acceptable.... why my risk of cancer recurrence doesn't matter suddenly. I worry that if I have a recurrence of will be more advanced than it would have been pre covid. And I worry there's no access to treatment." – **Female aged 55 with stage 1 breast cancer**

> "Because I have been told that my blood test and CT scan that was arranged for April has been postponed indefinitely! The letter says if I haven't received a new appointment within a year, then I should contact them!!!" – **Male aged 67 with stage 1 gastrointestinal cancer**

> "Taken 5 weeks to get MRI scan, still waiting results. Do not know what I am up against, No contact from the hospital don't know who I came under as it was the middle of the night. Frustrating." – **Female aged 68 with dentral nervous system and genitourinary cancer (stage not disclosed)**

3.1.1 Estimated social economic status

There were no significant differences by social economic status, with 42% of those from less deprived groups reporting they had been impacted and 43% from more deprived groups reporting they had been impacted (p = .055).

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7 A composite variable is a variable created by combining two or more individual variables, called indicators, into a single variable. Composite variables are used to measure multidimensional concepts that are not easily observed.

3.1.2 Cancer type

Findings were fairly consistent by all cancer types, with around two fifths of cancer patients reporting being impacted. There was a 14-percentage point difference between the least and most impacted cancer types below, however this was not statistically significant (p = .03). The table below (**Table 3**) only reports a sample of the cancer types with a base sample size of 100 or more.

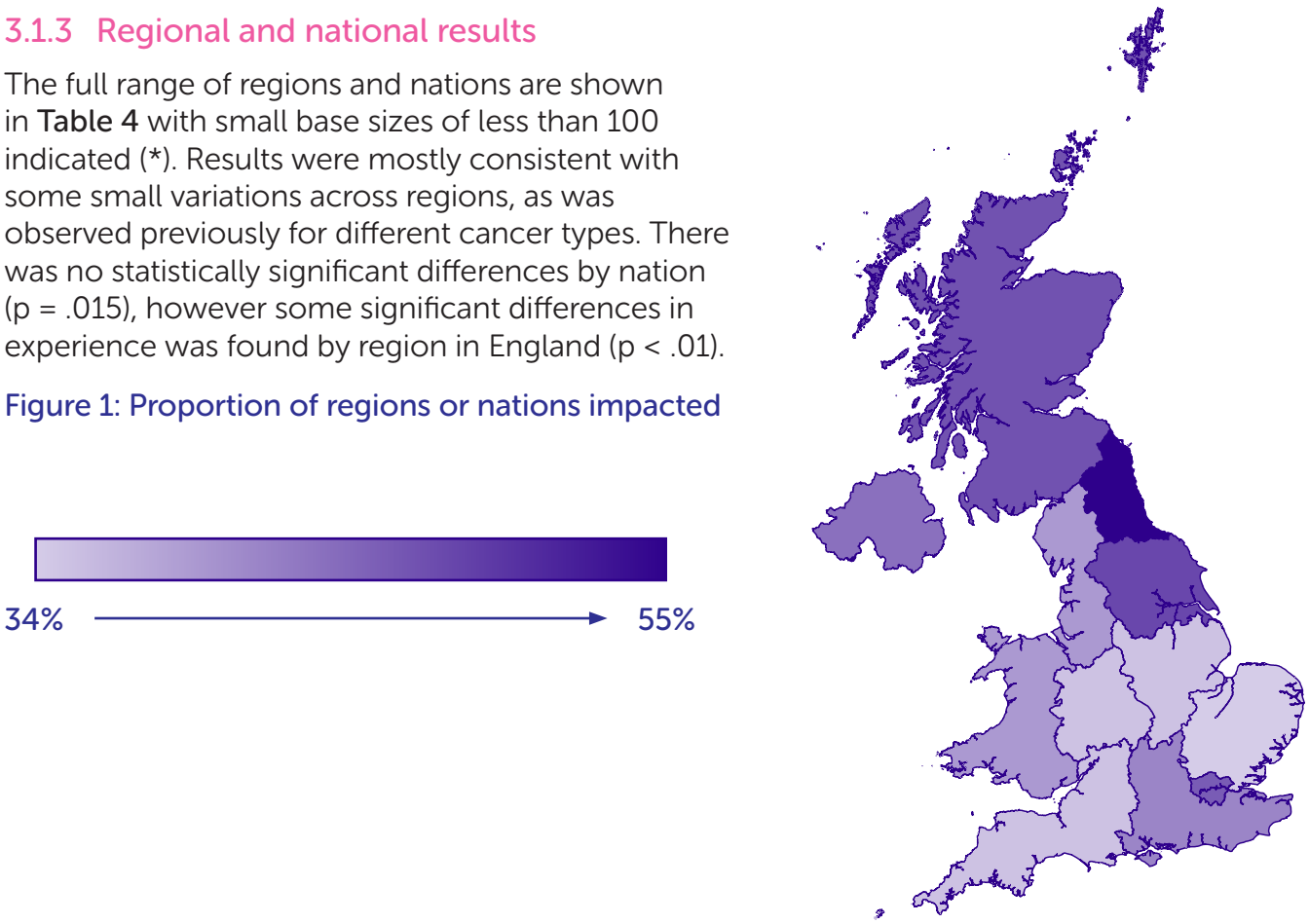
Table 3: Proportion of cancer types impacted (sample size of >100)

Cancer type	Impacted	No. of cancer patients
Multiple selections made[8]	47%	143
Gastrointestinal (including colon, rectal, anal, stomach, intestinal, oesophageal)	45%	160
Gynaecological (including uterine, cervical, ovarian, vaginal, vulvar)	43%	125
Genitourinary (including bladder, kidney, prostate, testicular)	42%	241
Breast	40%	433
Blood (including leukemia, lymphoma, Hodgkin and non-Hodgkin lymphoma, multiple myeloma)	33%	212

3.1.3 Regional and national results

The full range of regions and nations are shown in **Table 4** with small base sizes of less than 100 indicated (*). Results were mostly consistent with some small variations across regions, as was observed previously for different cancer types. There was no statistically significant differences by nation (p = .015), however some significant differences in experience was found by region in England (p < .01).

Figure 1: Proportion of regions or nations impacted



8 When asked which cancer site was applicable to them, some respondents ticked more than one. It is unclear whether these refer to multiple primaries or one primary with metastases. We have therefore grouped these together.

Table 4: Proportion of regions or nations impacted

Nation and region	Impacted	No. of cancer patients
England – North East	55%	59*
England – Yorkshire and Humberside	48%	143
Scotland	47%	108
England – London	46%	147
Northern Ireland	44%	18*
England – South East	42%	320
Net England	41%	1,374
England – North West	40%	177
Wales	40%	74*
England – West Midlands	36%	122
England – East Midlands	36%	111
England – South West	36%	169
England – East Anglia	34%	126
Prefer not to say	9%	7*

3.2 Impact on treatment

In this report treatment comprised of a range of treatment including clinical trials, long term treatment and anti-cancer medication. Where this is reported as impacted, this means that the treatment cancer patients would usually expect was reported to be delayed, cancelled and/or they received different treatment to what they had expected or planned.

54% of cancer patients reported that their treatment had continued as expected, while 33% reported they had been impacted in at least one way. Of those who stated that they were currently undergoing treatment or due to start treatment, **53% reported their treatment continued as expected, and 36% reported that they were impacted in at least one way.** Here are some examples of how cancer patients' treatment had been affected:

> "Afraid that if I don't get the treatment that I need in time, the tumour will grow more and more complex surgery or treatment will be needed." – Female aged 63 with stage 4 lung and gastrointestinal cancer

> "I would have liked my planned treatment to continue as originally set out and am frustrated by not really knowing why things have by stopped or postponed. Without a Scan I don't understand how the decision to change was made." – Male aged 77 with stage 3 genitourinary cancer

> "Supported by family and friends and work. Oncology team are great plus fortnightly phone call from extremely vulnerable county council support team. COVID has allowed me to concentrate on my chemo treatment in a safe space and not to have to worry about normal routine – travelling, school drop off etc." – Female aged 58 with breast cancer (stage not disclosed)

" Because my treatment has been postponed when I need it most. My cancer has already spread to the lymph nodes and I worry the longer I am left untreated, with ZERO emotional mental health support, the worse I become or that the cancer spreads further." – Male aged 60 with stage 3 genitourinary cancer

3.2.1 Estimated social economic status

There were no significant differences by social economic status, with 34% from less deprived groups and 34% from more deprived groups reporting they had been impacted (p = .011).

3.2.2 Cancer Type

Findings were fairly consistent for all cancer types, with around one third of cancer patients being impacted. However, the difference between the least and most impacted cancer types (7 percentage points) suggests some slight differences in experience by cancer type. When tested for statistical significance, the result was not significant (p = .049). The table below (**Table 5**) only reports cancer types with a base sample size of 100 or more.

Table 5: Proportion of those impacted broken down by cancer type

Cancer type	Impacted	No. of cancer patients
Gastrointestinal (including colon, rectal, anal, stomach, intestinal, oesophageal)	35%	138
Breast	35%	440
Multiple selections made	32%	133
Genitourinary (including bladder, kidney, prostate, testicular)	32%	208
Blood (including leukemia, lymphoma, Hodgkin and non-Hodgkin lymphoma, multiple myeloma)	32%	192
Gynaecological (including uterine, cervical, ovarian, vaginal, vulvar)	28%	120

3.2.3 Regional and national results

The full range of regions and nations are shown in **Table 6** with small base sizes of less than 100 indicated (*). Results were mostly consistent with some small variations across regions. As was observed previously there was no statistically significant differences by nation (p = .101), but region had possible significant differences in experience in England (p < .01).

Figure 2: Proportion of those impacted broken down by nation and region

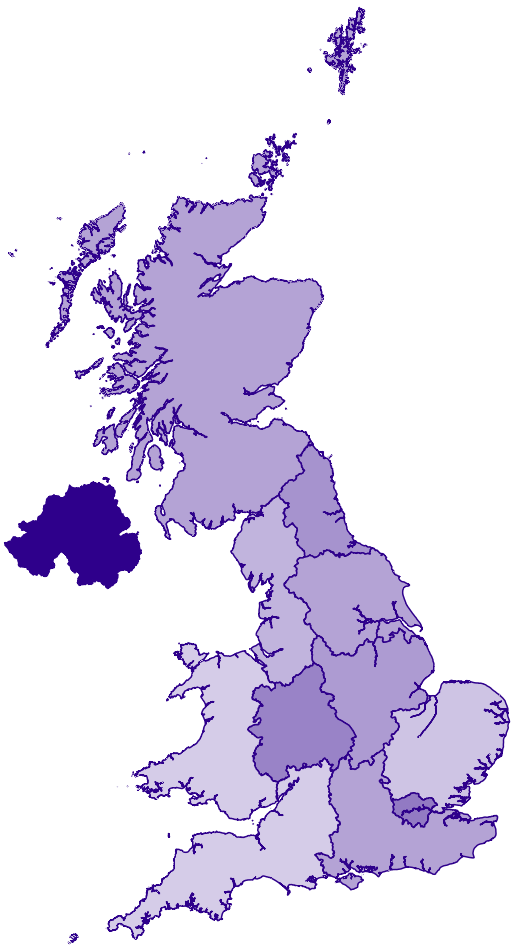


Table 6: Proportion of those impacted broken down by nation and region

Nation and region	Impacted	No of cancer patients
Northern Ireland	53%	17*
England – London	38%	125
England – West Midlands	37%	124
England – North East	35%	53*
England – East Midlands	34%	110
Scotland	33%	97*
Net England	33%	1,267
England – Yorkshire and Humberside	33%	129
England – South East	33%	301
England – North West	31%	157
England – East Anglia	29%	113
England – South West	28%	155
Wales	27%	70*
Prefer not to say	24%	6*

3.3 Testing or treatment location

Cancer patients who reported their testing and treatment had continued as expected were asked where their treatment continued. 71% indicated treatment continued at the same hospital as usual. There were no significant differences by nation, region, SES or cancer type ($p > .01$ for all).

Table 7: Proportion of cancer patients who continued care at the same or a different hospital

Statement [9]	Weighted %
My treatment was continued at the same hospital as usual	71%
Prefer not to say	13%
My treatment was continued at a different hospital	7%
My treatment was continued at the same hospital as usual, but in a different part of the hospital	6%
My treatment was continued at the same hospital as usual but in a different part of the hospital that I know is a 'COVID-19 free zone'	5%
My treatment was continued at a private hospital	5%
My treatment was continued at a different hospital that I know has a 'COVID-19 free zone' or is COVID-19 free.	4%
My treatment was continued at a different hospital that is further away	1%
My treatment was continued at a different hospital that is closer	1%

3.4 Impact on care

In this report 'care' is defined as everything patients would expect as part of their care. For example, support for their emotional well-being or mental health, physiotherapy, and reconstructive surgery. Unlike testing and treatment, care includes elements of the cancer journey less specific to outcomes and survival. Where care is reported to be impacted this means that patients did not receive the care they expected, the standard or quality of the care they would expect was not delivered or there was a change to how it was delivered.

29% of cancer patients stated their care had continued as expected, while 64% said they had been impacted in at least one way. Here are some examples of how cancer patients' care had been affected:

> "I just don't feel I'm getting the same support any more. I've always been very positive during my appointments but now feel that because of that they don't seem concerned about me. I phoned up to ask advice about how I should feel after my surgery and for a few problems I had and didn't get call back. My medication needs changing and my oncologist cancelled my appointments not even phoning up. Other people seem to be getting this support so I don't understand why I'm not" – Female aged 48 with breast cancer, stage not disclosed

9 Participants could select more than one of some statements to indicate for example if their care had continued at their usual hospital which was also a private hospital, etc.

"My diagnosis is terminal and I wish I could attend support groups consisting of other terminal patients. It's been upsetting coping with this without easy access to emotional support services" – Male aged 33 with stage 4 lung and gastrointestinal cancer

"Because I feel abandoned by services" – Female aged 61 with stage 4 lung and gynaecological cancer

"I know my cancer has spread but I feel that I have been abandoned. Two phone appointments with my Oncologist were cancelled and instead I spoke with a pharmacist and a nurse. I have since spoken to my Oncologist and have been in hospital for five days where I had another scan. I am still waiting to speak to someone to know if I can have treatment. I am very scared. I don't want to die during this COVID outbreak without seeing my loved ones." – Female aged 73 with stage 4 lung and breast cancer

3.3.1 Estimated social economic status

Of all areas surveyed, impact on care had the largest variation by social economic status with 66% of those from a less deprived group reporting they had been impacted, and 61% from more deprived groups reporting they had been impacted. These differences were possibly significant ($p < .01$).

3.3.2 Cancer type

Of all areas surveyed, impact on care had the largest variation by cancer type with a maximum percentage point difference of 20 percentage points, between gastrointestinal/genitourinary and those with gynaecological cancer types. This differences was possibly significant ($p < .01$).

Table 8: Proportion of those impacted broken down by cancer type

Cancer type	Impacted	No. of cancer patients
Gynaecological (including uterine, cervical, ovarian, vaginal, vulvar)	78%	137
Multiple selections made	71%	151
Breast	66%	487
Blood (including leukemia, lymphoma, Hodgkin and non-Hodgkin lymphoma, multiple myeloma)	64%	230
Gastrointestinal (including colon, rectal, anal, stomach, intestinal, oesophageal)	61%	166
Genitourinary (including bladder, kidney, prostate, testicular)	58%	247

3.3.3 Regional and national results

The full range of regions and nations are shown in **Table 9** with small base sizes of less than 100 indicated (*). Of all areas surveyed, the results for care showed the most variation in experience. These differences were possibly significant by nation ($p < .01$) and by region in England ($p < .01$).

Figure 3: Proportion of those impacted broken down by region and nation

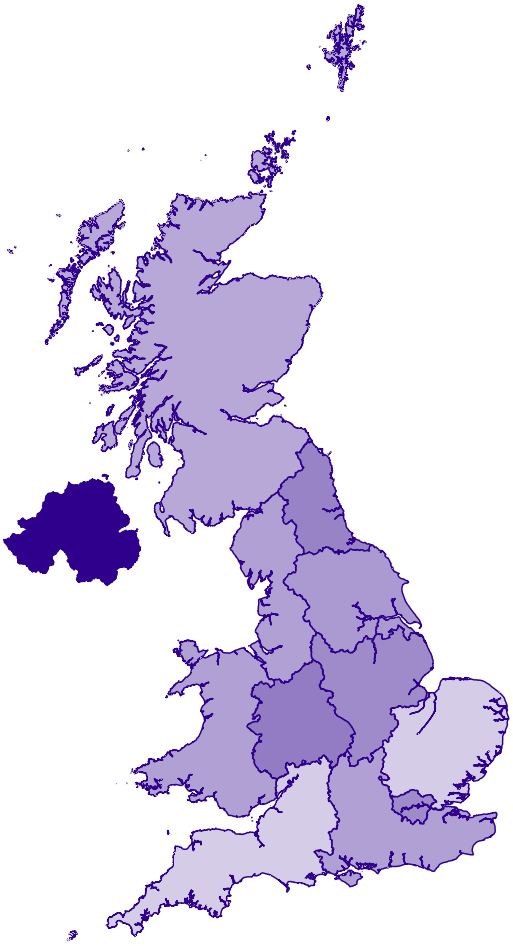


Table 9: Proportion of those impacted by region and nation

Nation and region	Impacted	No. of cancer patients
Northern Ireland	85%	21*
England – West Midlands	68%	138
England – North East	67%	66*
England – London	66%	147
England – East Midlands	66%	127
England – Yorkshire and Humberside	64%	149
Net England	63%	1,480
Wales	63%	80*
England – North West	63%	188
England – South East	63%	349
Scotland	62%	111
England – East Anglia	57%	138
England – South West	56%	178
Prefer not to say	33%	7*

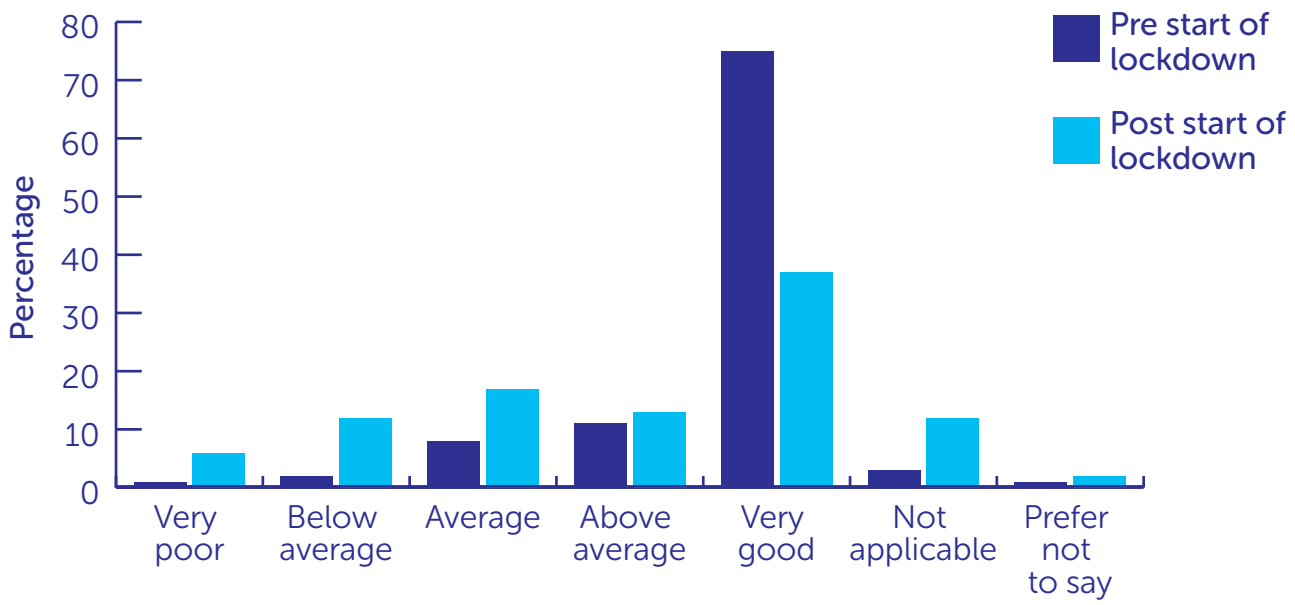
3.4 Overall cancer care rating

Cancer patients were asked to provide a rating of their overall care **before** and **since** lockdown began. There was a significant reduction in those rating their overall care as 'very good' from 75% to 37% ($p < .000125$)[10]. Although there was an increase in those who selected 'not applicable', this isn't sufficient to explain the large drop. We also saw increases in those rating their care as 'very poor', 'below average', and 'average'. This suggests that cancer patients overall cancer care has worsened since the start of lockdown.

Table 10: Proportion of those who rated their care overall from very poor to very good

Overall rating of care overall	Pre	Post
Very poor	1%	6%
Below average	2%	12%
Average	8%	17%
Above average	11%	13%
Very good	75%	37%
Not applicable	3%	12%
Prefer not to say	1%	2%

Figure 4: Proportion of those who rated their care overall from very poor to very good.



10 McNemar chi-sq test was conducted on grouped responses. Those responding 'very good'/'above average' vs those responding 'average'/'below average'/'very poor', pre and post. Results were significant, even against the bonferri correction threshold of 0.000125.

3.5 Summary of impact on cancer services

- Around two fifths of cancer patients had their testing impacted in at least one way since lockdown began on 23 March 2020.
- One third of cancer patients had their treatment impacted in at least one way since lockdown began on 23 March 2020.
- Almost two thirds of cancer patients had their care impacted in at least one way, and when asked to rate their cancer care overall before and since lockdown started, there was a significant decrease in those rating their care as 'very good' from three quarters to one third.
- There does not appear to be large differences by estimated social status for either testing or treatment. The largest difference in experience by deprivation was found for care, although this was relatively small it may be significant ($p < .01$).
- Although breakdowns by cancer type and nation suggest some minor differences for testing and treatment, neither were significant. However possible significant differences for cancer type and nation were found for care ($p < .01$).
- Differences by region in England was found to be possibly significant for testing, treatment and care ($p < .01$).

It's possible there are significant differences in experience by cancer type which we've been unable to detect. A larger cohort of cancer patients would be required to study this in more detail for all cancer types including rarer cancer types.

Lorraine, 47, London

Multiple myeloma, diagnosed 2014

"I'm anxious because I am worrying about my family (I have elderly parents) and am terrified if they or I become ill with COVID-19. At the moment my chemotherapy is continuing as normal (although in a different part of the hospital) and I am worried about the potential changes to my treatment due to the impact of the virus on the NHS.

"I do think the covid pandemic has made my anxiety worse... I do consider myself one of the lucky ones that my treatment has continued."

Mo, 47, Runcorn

Brain tumour, diagnosed 2017

"I filled out the survey because I wanted to reflect how I feel at this time. COVID-19 has led to me being even more careful about staying in, and I wanted to share this experience to help others."

Joe, 62, Derby

Lung cancer, diagnosed 2008

"Totally following the government and medical advice on shielding, working from home and finally getting home delivery slots from my local shop, having been in receipt of care parcels from my local council until I secured the delivery slot, I feel well looked after and well protected such that I can shield."

4 Emotional impact of the pandemic on cancer patients

4.1 Impact of delays and cancellations of testing and treatment on cancer patients' well-being

Cancer patients who indicated that they had had their testing and treatment delayed or cancelled were asked if they had received a new date for their tests or treatment. 16% had been notified for some elements but not others, and **68% had not been notified.**

A follow up question asked if this had made them **feel more**, **less** or **the same** of a list of emotions. The most common emotions that were **felt more** were **'frustrated', 'anxious'** and **'afraid'.** The most common emotions **felt less** were **'optimistic'** and **'safe'**[11].

Table 11: The most commonly selected emotions felt more or less as a result of the change of their cancer testing and treatment.

Emotion	Proportion selected
Frustrated	72% felt this more
Anxious	68% felt this more
Afraid	59% felt this more
Optimistic	66% felt this less
Safe	64% felt this less

4.2 How have people with cancer been feeling since lockdown began?

All cancer patients were asked how they have been feeling since the start of lockdown. The most common emotional responses were **'anxious'** and **'frustrated'**. When asked to **select just one emotion**, just under one quarter selected that they felt anxious, and a fifth selected they felt frustrated. This was maintained as the top two responses when analysing breakdowns by region and nation, estimated social economic status and cancer type[12].

Table 12: proportion of emotions selected by cancer patients to describe how they have been feeling since lockdown began

Emotion	Proportion selected
Anxious	23.9%
Frustrated	21.5%
No response	17.4%
Optimistic	7.5%
Afraid	6.6%
Safe	6.5%
Multiple	5.4%
Alone	4.2%

11 Further breakdowns are not provided with this question as it was only presented to a sub group of 131 cancer patients who stated their testing and treatment had been impacted.

12 This question was presented to all cancer patients n = 1,842.

Emotion	Proportion selected
Upset	2.3%
Overwhelmed	2.2%
Hopeless	1.2%
Prefer not to say	1.1%
Helpless	0.1%

4.3 What is worrying cancer patients most?

Cancer patients were asked what they were instead most worried or stressed about. The top three responses were 'becoming seriously ill from COVID-19', 'catching COVID-19', and 'the impact lockdown is having on my cancer treatment and care'. The worry or stress that was least reported was 'home schooling' and 'losing your job/unemployment'. For a full breakdown see below.

Table 13: What are cancer patients most concerned or worried about?

Concern/worry [13]	Proportion who selected
Becoming seriously ill from COVID-19	46%
Catching COVID-19	45%
The impact lockdown is having on my cancer treatment and care	36%
Attending hospital appointments during the outbreak	34%
Friends or family living outside your household	33%
Future plans	32%
Not being able to sleep	28%
Dying alone	18%
Finances	17%
Your own safety / security	16%
Getting medication	14%
Getting food	13%
Work (even if you feel your job is safe)	10%
Friends or family living in your household	10%
None of these	8%
Marriage or other romantic relationship	7%
Losing your job / unemployment	7%
Other, please specify	6%
Home schooling	5%
Prefer not to say	0%

13 People could select more than one concern or worry

4.4 Shielding

- 50% of cancer patients surveyed advised they were in the shielding group
- 6% expected a shielding letter and did not get one
- 9% chose to shield despite not getting a letter to advise they needed to

When asked if they were given adequate advice on shielding:

- 79% of cancer patients who had advised previously they were shielding agreed
- 18% agreed that they were unsure if they should be shielding
- 81% agreed that they knew how to access support while shielding

4.5 A qualitative analysis of open text survey comments

1,549 open text comments were reported by cancer patients explaining in more detail the impact COVID-19 had on them. These were analysed to yield 2,066 codes that were grouped into 36 broader themes. The most common themes are discussed below. Further details on the themes and codes identified can be found in the appendices. The seven most commonly reported themes were: treatment, COVID-19 concerns/'coronaphobia', inability to live life/ remainder of life, missing interactions, care, testing and the future.

4.5.1 Theme 1: Treatment

A large proportion of cancer patients were anxious that their treatment had been stopped and therefore if their cancer returned or spread, they would not be able to survive. Some of those patients believed that their treatment had been postponed or cancelled due to COVID-19 patients being prioritised. Participants were also anxious about attending their appointments and fearful of contracting COVID-19 while in hospital:

> "I am anxious that my cancer will be left untreated for too long, or that I will have to go into hospital for treatment and may catch COVID." – **Female aged 82, with stage 3 blood cancer**

> "Because I need surgery and have been told without COVID-19 it would have taken place by now." – **Female aged 59, with stage 3 gastrointestinal cancer**

Some cancer patients felt frustrated that cancer trials had been postponed or cancelled and felt that COVID-19 research was being prioritised:

> "I am frustrated that the Marsden effectively massively reduced its clinical trials due to COVID and felt that it should have not been affected and trials should have continued without change" – **Male aged 51, with stage 3 gastrointestinal cancer**

4.5.2 Theme 2: COVID-19 concerns/'coronaphobia'

Most cancer patients reported feeling anxious and afraid of contracting COVID-19, especially as they felt high risk and therefore that they would not survive. For some this was exacerbated by negative information shared by the media stating that at-risk individuals would not survive COVID-19:

> "I am afraid that I will catch the virus and with my underlying conditions I will die." – Male aged 68, with stage 4 genitourinary cancer

> "Because the media and stats have basically given us cancer and chemo patients a death sentence. There is no positive stats about chemo/cancer patients. We're scared of cancer and this virus. Treatments have been changed and could affect out prognosis. We don't get to speak to our consultants face to face. It's horrific to be treated this way. I'm only 40 with young children and my whole life is up in the air with no help or support even from loved ones because of the shielding." – Female aged 40, with stage 2 breast cancer

While most were concerned about the impact of COVID-19 on their health, some reported feeling anxious about the potential impact on family members and friends, the NHS and society as a whole:

> "I am anxious about the huge loss of life, the impact of the pandemic on society, the thought of it directly affecting family and friends" – Female aged 57 (cancer type and stage not known)

> "Afraid, for family, friends, NHS , and what the world will be. It is polarizing between those that care and not, those who can get by and not" – Female aged 61, with stage 3 gastrointestinal cancer

4.5.3 Theme 3: Inability to live life / Inability to live remainder of life

A large proportion of cancer patients were frustrated at the inability to live their life, with those with a terminal diagnosis reporting to feel upset and frustration at not being able to live the remainder of their life as they had hoped. Many reported that following their cancer treatment and the required isolation during their treatment, plans they had made including spending time with friends and family and travelling had now been cancelled. Many also reported that they felt they had been shielding and isolated for an extended period, firstly due to cancer and associated treatment and now due to COVID-19, leading to feelings of isolation and loneliness:

> "I have incurable cancer and I do not know how long I have got. Therefore I did get very upset that all the nice things I was managing to do – going to music events, singing, meeting friends and family, short breaks, meals out – have all stopped and, for me, they may never start again. I am hoping I can last out. I am making the most of what I have got." – Female aged 65, with stage 3 gynecological cancer

> "I feel overwhelmed with the whole situation. I had dealt well with my cancer diagnosis and was looking forward to getting my life back this year as treatment reduced. I run my own business which has been completely decimated. It just feels too much." – Female aged 41, with stage 3 breast cancer

4.5.4 Theme 4: Missing interactions

Most cancer patients expressed frustration that they could not currently interact with family members or friends and fear that they may never see them again due to a terminal diagnosis. While most cancer patients reported using technology to stay in contact, many missed human contact and physical interactions with their loved ones, specifically new arrivals within the family. Some cancer patients also described living alone and therefore that the inability to see or interact face-to-face with loved ones was especially difficult. Moreover, as was also mentioned in the previous theme, several cancer patients had been isolating previously due to their

diagnosis and treatment, they felt additionally isolated as they had not seen their loved ones for a very extended period:

> "Very hard not to see friends and family especially after isolation last year due to being immunosuppressed." – **Female aged 69, with stage 4 blood cancer**

> "Because I'm desperate to see my family and friends again in person and not just via video links." – **Male aged 70, with stage 1 genitourinary cancer**

4.5.5 Theme 5: Care

Many cancer patients were frustrated with the current state of their cancer care, detailing that they felt abandoned and forgotten, with COVID-19 patients being prioritised and afraid that they may die as a result of delays. Participants reported that they had experienced delays and now struggled to get appointments, with some also described the changes to their care, including the difficulty they experienced with consultations taking place over the phone.

> "Not getting the support and care I need. Feel as though I have been forgotten. My telephone appointment with oncologist has been postponed from May to end of August with no support in between from specialist nurses etc." – **Male aged 68, with stage 4 central nervous system, brain or eye cancer**

> "I have felt afraid that my cancer care will be compromised and that I will be forgotten. I feel afraid that I will become invisible and die as a result of missed opportunities to screen and detect my growing tumours." – **Female aged 53, with stage 1 lung cancer**

4.5.6 Theme 6: Testing

Many cancer patients reported feeling anxious, frustrated and afraid that their cancer tests had been postponed, delayed or cancelled and expressed fear that by the time the tests were rescheduled, cancer may have spread to a non-treatable stage. As with treatment changes, delays and cancellations, some cancer patients believed this delay was a result of COVID-19 patients being prioritised:

> "Not being able to have scheduled mammograms which is causing me to feel anxious and emotional." – **Female aged 59, with stage 2 breast cancer**

> "I am very anxious and worry that if the cancer comes back during COVID 19 that it will be missed as I am not having regular MRI scans. The cancer coming back is my greatest fear at the minute." – **Female aged 40, with stage 2 gynecological cancer**

4.5.7 Theme 7: Future

Many cancer patients felt anxious about the future and the impact that COVID-19 will have on the individual, their family and the country, describing their frustration about the uncertainty. Some also reported feeling anxiety about potential changes to the lockdown and were concerned about their health when lockdown eases in the future. Many were also anxious about the duration they would be required to shield and some were hopeful that they will be allowed to leave their homes again soon:

> "Anxious about the future – will I have to shield for months? Now that I am retired I enjoy travelling but can't see that happening for some time." – **Female aged 66, with stage 1 blood cancer**

> "Not knowing when we will resume normality." – Male aged 66, with stage 4 lung cancer

However, a few cancer patients felt optimistic that the lockdown will have positive future implications.

> "I can't help feeling this pandemic might do for our children and our childrens' children what the wars did for our parents and their parents... awaken their social sensibilities and responsibilities, knock some sense into them and persuade them to value life, relationships and the planet we live on." – Male aged 72, with stage 1 genitourinary cancer

4.6 Summary of the emotional impact of the pandemic on cancer patients

Overall the most common emotions reported by cancer patients were anxious and frustrated. These were also the most common emotions across cancer type, nation, region and social economic status, and those who reported their testing and treatment were impacted.

Cancer patients' lifestyles have clearly been impacted with around half of cancer patients surveyed advising that they were shielding as advised by their shielding letter. The very nature of shielding requires a considerable change from daily life for many people, and those who had plans for how they hoped to live out the remainder of their lives (in the cases of terminal cancer diagnoses) reported they found this particularly difficult.

Just under one in ten cancer patients stated that they were shielding despite not receiving information to do so suggesting concern regarding contracting COVID-19. This concern about COVID-19 was apparent from commonly reported concerns about 'catching COVID-19' or 'becoming seriously ill from COVID-19', and the analysis of the open text survey comments. There was also some frustration that COVID-19 patients were being prioritised over cancer patients, with testing and treatment delayed or cancelled. For further tables from the quantitative analysis see Appendix 1 and for the qualitative table of codes and themes see Appendix 2[14].

The next section will explore what cancer patients said they want and need from the government going forward.

14 Appendices available on request from the author Charlotte Ide – charlotte.ide@cancer.org.uk

Mary, 49, Bridgend, Wales

Endometrial cancer, diagnosed 2020

"I had surgery followed by radiotherapy and was concerned about whether chemotherapy was not given because of COVID-19. I had a good experience of having radiotherapy treatment and the staff were amazing throughout."

Jan, 66, London

Breast cancer, first diagnosed 2005

"I am staying in because of COVID-19 – my only excitement is going to the Marsden. I am in and out and then home. It is so close so I am lucky. I am in and out with the bloods and then it's a phone consultation – it actually saves time."

Alfred, 62, London

Advanced prostate cancer, diagnosed 2012

"COVID-19 has brought so much confusion and fear within the cancer community. By sharing my experience, I wanted to help give a better understanding of what is going on out there. I want to be part of the evidence that gives the bigger picture and can help make changes for the better."

5 What do people with cancer think the government should be doing now and after COVID-19?

5.1 Now

The most endorsed government actions during the COVID-19 pandemic were 'offer a safe environment, such as a COVID-19 protected zone, for cancer patients to be treated', followed by 'ensure NHS staff have adequate access to Personal Protection Equipment (PPE)'. The action with the lowest support was 'improve messaging to the public that the NHS is still open and encourage them to seek help'.

Table 14: proportion of those who support policy calls/actions by government during the pandemic

Policy/action	Proportion who supported this action
Offer a safe environment, such as a COVID-19 free zone, for cancer patients to be treated	88%
Ensure NHS staff have adequate access to Personal Protection Equipment (PPE)	86%
Ensure NHS staff and cancer patients are regularly tested for COVID-19, regardless of if they have symptoms or not as they may be asymptomatic (possibly carrying the virus but won't show any symptoms) or pre-symptomatic (not showing symptoms yet)	84%
Ensure that patients who have potential symptoms of cancer can be tested	84%
Improve messaging to the public that the NHS is still open and encourage them to seek help	60%

5.2 After COVID-19

The most endorsed government actions after the COVID-19 pandemic were 'reinstate cancer screening programmes as quickly as possible', followed by 'ensure adequate capacity in diagnostic services to cope with the backlog in potential cancer diagnoses'. The action with the lowest support was 'smokers to have universal access to stop smoking services to help them quit'.

Table 15: proportion of those who support policy calls/actions by government after the pandemic

Policy/action	Proportion who supported this action
Reinstate cancer screening programmes as quickly as possible	92%
Ensure adequate capacity in diagnostic services to cope with the backlog in potential cancer diagnoses	86%
Treatment services return to pre COVID-19 levels as quickly as possible	85%
Ensure clinical trials are restarted as quickly and safely as possible	79%
Revise cancer workforce plans to ensure diagnostic and treatment services can meet growing future demand	75%
Innovations in the NHS service (e.g. new or alternative ways of communicating, testing or treating) that seem effective during the pandemic become new systemic ways of working	69%
Smokers to have universal access to stop smoking services to help them quit	36%

5.3 Summary of what people with cancer want from CRUK and the government now and after COVID

There was strong support for the cancer service related policies. The focus was very much on policies related to measures that would enable treatment to continue safely during the pandemic such as adequate PPE and safe spaces. After COVID-19 there was strong support for returning services to their pre-COVID-19 conditions and reinstating cancer screening programmes.

6 Concluding remarks

Behind every statistic is a real person and, in this case, real cancer patients talking about the real impact of the COVID-19 pandemic on their real lives and cancer care. Overall, for many cancer patients the COVID-19 pandemic appears to have had a significant impact on their testing and treatment, and most notably their care.

COVID-19 and the impact on their testing, treatment and care has resulted in a negative impact on the emotional well-being of many cancer patients whether they were hoping to finish their treatment, find out the results of their test, have their regular screening, or continue with care that could support them, in some cases for the remainder of their life.

For the majority of cancer patients,the government actions cancer patients most strongly support were: to put in place and keep in place practices including PPE and safe spaces that allow cancer patients testing, treatment and care to continue safely; and to put in place measures to address the backlog of cancer patients and ensure screening and diagnostic capacity is returned to normal as quickly as possible.

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