Cancer Research UK
Cancer Patient Survey 2021

CRUK's second survey studying the impact of COVID-19 on cancer patients in the UK

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How to reference

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Cancer Research UK

Cancer Research UK is the world's largest independent cancer charity dedicated to saving lives through research. In 2020/21 we spent £421m on new and ongoing research projects. We receive no funding from Government for our research.

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http://www.cancerresearchuk.org/

Contents

1 Executive summary

1.1 Background and approach

Cancer Research UK conducted a survey of cancer patients May 1st – May 28th 2020, early into the pandemic, to understand their perspectives on the initial impact COVID-19 was having on their testing, treatment and care. Findings can be found here (CRUK, 2020). This report shares the findings of a second survey of N=900 cancer patients conducted December 21st 2020 - March 25th 2021. The survey aimed to build a more complete understanding of how cancer patients' perspectives of how their testing, treatment and care had been impacted by the pandemic since it began as well as impact on wellbeing and what they wanted the government to be doing. The survey also included new questions on clinical trials, COVID-19 safety measures, remote consultations and community-based treatment.

1.2 Key Findings

- Around 1 in 3 (34%) cancer patients reported that their testing had been impacted since the start of the pandemic.
- Almost 1 in 3 (29%) cancer patients reported that their treatment had been impacted since the start of the pandemic.
- Cancer patients who experienced delays and cancellations reported waiting on average 13.4 weeks for tests and 13.5 weeks for treatment
- Around 4 in 5 (80%) reported that their care had been impacted in at least one way. The most common ways they were affected was going to treatment alone, having check-ups at hospital cancelled or postponed, and receiving less support both from support groups and clinical nurse specialists.
- The proportion of cancer patients who rated their overall cancer care as 'very good' reduced from 84% for before the pandemic started (retrospective rating) to 60% since the pandemic started, 33% downgraded their rating since the pandemic started.
- The majority of cancer patients reported positive experiences of COVID-19 safety measures, particularly safe spaces (89%), wearing masks (80%) and home and community-based treatment (75%).
- The most reported concern generally was of becoming seriously ill from COVID-19 (50%) and catching COVID-19 (49%).
- Patients reported feeling more "frustrated" (67%) and more "anxious" (62%) compared to before pandemic.
- The most highly endorsed Government actions related to ensuring those with signs and symptoms of cancer get diagnosed as quickly as possible (94%), and adequate capacity is put in place to address the backlog (92%).

1.3 Conclusions, recommendations and implications

Similar findings to the first survey were found in terms of more cancer patients reported that their testing or treatment had continued as expected or planned. However, there are still many cancer patients who feel they have been left behind, reporting delays, cancellations, and changes to tests and treatment, and impact to their care.

2 Introduction

2.1 Background

Even before the current COVID-19 pandemic, cancer services were on the verge of crisis. Cancer waiting time targets were routinely missed across the UK. This has been largely driven by long term underinvestment and lack of strategic direction to grow capacity of resources for an increasingly stretched cancer service. Though cancer survival has improved in recent decades, our progress has lagged behind comparable countries – meaning the UK is far off claiming the mantle of having world class cancer services (International Cancer Benchmarking Partnership, 2021).

Cancer is the leading cause of death in the UK[1] (CRUK, accessed July 2021), and cancer doesn't just stop because of a pandemic, however the first and subsequent waves of the pandemic have exacerbated the significant pressures the NHS and its workforce were already under. Although significant efforts have been made to maintain cancer screening, diagnostic testing and treatment, thousands of people on the cancer pathway have been impacted. For example, the number of people waiting over 6 weeks for one of seven diagnostic tests commonly used to diagnose cancer was seven times higher in May 2021 compared to May 2019 in England (CRUK, 2021). And nearly 45,000 fewer people began treatment for cancer in the UK between April 2020 and March 2021 compared with pre-pandemic, a reduction of 12% (CRUK, 2021).

Although some cancer services metrics are now broadly similar to or are beginning to exceed pre-pandemic levels (CRUK, 2021),
we would expect higher numbers in 2021 given underlying trends pre-pandemic, and we need cancer services to markedly exceed previous performance in order to provide tests and treatments that were missed whilst capacity was reduced. Getting back to where we were is still not enough, and this suggests we are not equipped to deal with cancer demands and potential future increases in demands from COVID-19, or potentially other NHS pressure surges.

2.2 Previous CRUK cancer patient experience survey findings

A survey of cancer patients in the UK was previously conducted by Cancer Research UK in May 2020, around the first peak of the COVID-19 pandemic (the first nationwide lockdown started 23rd March 2020). This survey focused on understanding the patient perception of impact of the pandemic on their testing, treatment and care of cancer patients and gave an early indication of the experiences of cancer patients during the pandemic. We reported that there was still a large proportion of cancer patients who said they had experienced testing delays (2 in 5), treatment delays (1 in 3), and reduced quality of care with ratings of 'very good' care reducing from 75% before the pandemic started (retrospective rating) to 37% after the pandemic started. Regional differences in self-reported experiences of impact on testing, treatment and care were also found suggesting that some areas had been disproportionately impacted by the pandemic. Government actions that involved measures that allowed cancer testing, treatment and care to continue safely were the most highly endorsed. Full details from the first report are available (CRUK, 2020). There remained questions as to how this had

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[1] for males and females aged 1 and older

evolved since the first peak, which led to the development of a new survey to hear first-hand from cancer patients.

2.3 Research aims

The primary aim of this new survey was to build on previous findings to understand the impact of COVID-19 on cancer patients' perceptions of impact on their testing and treatment across approximately a year since the start of the pandemic (March 2020 – March 2021). This included new questions on length of delays, clinical trials, community-based treatment, remote consultations and additional COVID-19 safety measures.

The survey aimed to understand more about the experiences of cancer patients throughout the pandemic and identify what policies were most important to cancer patients in the UK, to inform future decision making.

3 Methods

3.1 Design and procedure

This was a cross-sectional online survey (data collection via an online platform from December 21st, 2020 – March 25th, 2021) where cancer patients who took part were asked to share their experiences of the testing treatment and care before and during the pandemic retrospectively. Data was collected opportunistically and via two paid social media advertisements (on Facebook and Instagram) to recruit typically underrepresented samples including young people with cancer (under 25s) and their parents (for anyone aged under 16). The survey was subject to face validity testing before being launched in order to test for any errors, but also to ensure that it was as relevant as possible for cancer patients. Specifically, questions were validated through telephone interviews (n=7; for the first survey May 2020) and CRUK's 'Cancer Insights Network', an online feedback panel (n=5; for the adapted second survey).

3.2 Participants

900 cancer patients took part in this survey and the data was weighted to be representative of the UK by geography (nation)[2], estimated social status[3], and gender[4]. Participants were cancer patients from across the cancer pathway, from pre diagnosis to remission. However, the majority of cancer patients who took part in this survey were currently undergoing treatment (42%) or had just finished cancer treatment but were still being monitored (37%). 64% had been diagnosed before the pandemic had started, 35% had been diagnosed since the start of the pandemic less than 1% were waiting for their diagnosis to be confirmed.

The five most common cancer sites were: breast (25%), blood (16%), genitourinary (15%), gastrointestinal (12%), and gynaecological (6%), and 13% reported multiple tumour types. Stage distribution was broadly similar to that of the overall patient population (1 = 20%, 2 = 27%, 3 = 24% and 4= 18%). See tables 1-4 in Appendix 1 for full details on weighted results by point in the NHS cancer pathway, cancer stage, when patients were diagnosed around the

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[2] https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/mid2019estimates

[3] http://www.nrs.co.uk/nrs-print/lifestyle-and-classification-data/social-grade/

pandemic (before and after) and cancer types within this sample.

3.3 Measures

Measures specifically relate to:

- Self-reported perceived impact on their cancer testing
- Self-reported perceived impact on their cancer treatment
- Self-reported perceived impact on their cancer care
- Experience of COVID-19 safety measures
- Well-being
- Cancer patients support for government actions

3.4 Ethical Considerations

This research was conducted in accordance with the Market Research Society (MRS) Code of Conduct 2019 (MRS, 2019), and data was collected and has been stored in accordance with GDPR[4].

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[4] CRUK's privacy policy can be found here.

4 Self-reported impact on cancer services

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

4.1 Impact on Testing

Of the total sample (N=900), 519 cancer patients reported that they had been due testing (diagnostic or monitoring) since March 23rd 2020. In this report testing is defined as a wide range of clinical testing including scans to blood tests. The most common reason for cancer patients needing testing was for diagnostic purposes and the most common test type due was a blood test followed by CT scan. Where testing was reported as impacted, this meant that cancer patients reported the testing they would usually expect was delayed, cancelled, or changed to a different test to what they had expected or planned. It did not include those who chose not to have their tests due to COVID-19 or other reasons.

Of the 519 cancer patients who were due testing for their cancer since the start of the pandemic (March 23rd 2020), 66% stated that their testing had continued as expected or planned (n = 343)[5] and **34% reported that their testing had been impacted in at least one way** (n=176).

4.1.1 Demographic differences

Regional and National findings

There were no significant differences in those who had had their testing impacted since the start of the pandemic across the UK nations[6], but there were significant differences across regions in England[7] with the largest percentage point difference being observed for North East (65%) and the South East (19%). See table 1 for findings by UK nation, and table 2 for findings by region in England. See tables 5- 8 in appendix 1 for demographic details for regions across all devolved nations.

Table 1: Proportion impacted across UK nations

Nation	Total sample	Proportion Impacted
Scotland	N = 73	48%

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[5] Less than 1% chose not to have treatment due to COVID-19 (n = 1) or for another reason (n=1) suggesting that although some people who chose not to continue with testing as a result of the pandemic, they were a minority. Those who chose not to have testing were not included in the 'impacted' variable above.

[6] Nation: Pearson's Chi Square, *p* = .107;

[7] Region in England: Pearson's Chi Square, *p* = .002; statistically testing is not reported by region in Northern Ireland, Wales or Scotland as the sample sizes were underpowered.

Northern Ireland	N = 25	20%
Wales	N = 53	32%
England	N = 744	33%

Table 2: Proportion impacted across region in England

Region	**Total sample**	**Proportion Impacted**
North East	17	65%
North West	61	43%
London	49	41%
East Midlands	33	39%
South West	46	39%
West Midlands	27	33%
Yorkshire and Humberside	40	30%
East Anglia	56	21%
South East	98	19%

Gender, social grade and age

There were no significant differences in impact on testing by gender[8], social grade[9] or age[10].

Cancer stage

There were no significant differences in impact by cancer stage at diagnosis[11],[12].

4.1.2 Waiting times

Of the 137 cancer patients who indicated that their testing had been impacted by COVID-19, those who indicated they had experienced a delay or cancellation were asked how long in weeks they had to wait to be seen (n=115**). The average number of weeks cancer patients reported waiting for delayed or cancelled tests was 13.4 weeks** (IQR: 25th 4.18 weeks; 50th 8.43 weeks, 75th 17.24 weeks).

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[8] Gender: Fisher's exact Chi-square, *p* = .026

[9] SES: Pearson Chi-square, *p* .011

[10] Age: Pearson's correlation (R), *p* = .548

[11] Cancer stage at diagnosis, including those who did not know, or reported they prefer not to say: Pearson's Chi-square, *p* = .085

[12] Cancer type and test type were not studied further for statistically significant relationships due to sample size limitations for some types of cancer tests and tumour types.

4.1.3 Qualitative analysis

A total of 842 open text comments were provided by cancer patients in response to eight questions about the impact COVID-19 had on them and their testing. Of these 755 comments were from patients whose testing had been impacted. A further 87 comments were then analysed from patients who had experienced no changes to testing to ensure all experiences were considered to address the research questions. These comments were analysed thematically to better understand the experience of the those who had been impacted. **Six themes were identified: 'cancellation & delays', 'lack of communication', 'remote testing', 'private testing', 'primary and secondary care disputes' and 'lower risk'.**

Cancellation & delays

The most commonly reported changes to testing were delays and cancellations. For both delays and cancellations, longer delays (of one month or more) were more commonly reported than shorter term delays (of less than a month). Most patients did not report any substantial impact as a result of these changes. However, for a significant number this caused emotional distress, with feelings of anxiety, fear and anguish all reported. Linked to this was a feeling of uncertainty associated with the lack of clarity around their cancer status[13], with fear of reoccurrence or their cancer spreading common.

> "I finished chemo May 2020 and was due to have follow up scans and colonoscopy in November 2020. This would be my first scan monitoring since being diagnosed. As of yet I have no scans booked and have only been told that my bloods look ok. It's a terrifying time not knowing if I'm in remission and having no reassurance that scans will be booked." – ***32 year old female with gastrointestinal cancer, South East, England***

Concerningly slower diagnosis and delayed treatment due to delays or cancellations in testing was reported and in some cases delays to testing led to a deterioration in cancer patients' condition, requiring emergency intervention.

> *"I had an ultrasound which showed fluid on the lung so GP requested a CT on whole torso. Due the restrictions there was a backlog but the CT service resumed just as my request went in so there was a backlog of 6 weeks even though I was an emergency. By the time I had the scan my lung had collapsed." –* ***70 year old female with breast cancer, South East, England***

> *"My CT scan results were delayed by 2 weeks due to staff shortages due to Covid which delayed the start to my cancer treatment by 2 weeks." –* ***48 year old female with breast cancer, North west, England***

Lack of communication

A lack of clear and consistent communication around the changes to testing was apparent. Cancellation without being given an alternative date was common, leaving people with a sense of uncertainty and worry. Similarly, a lack of any information about the status or progress of their testing was also common. This meant a number of people had to actively

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[13] Here cancer status is a broad term referring to the current state of a patient's cancer or any changes to that state. For example, a patient's cancer being in a state of remission, whether their cancer has spread since previous testing, or whether a patient has a certain cancer, etc.

reach out and repeatedly seek clarity on what they could expect from their testing.

> *"Due to have monitoring appointment and tests following major (APR) surgery[14]…Further appointment scheduled for September has been cancelled and so far not rescheduled. I have tried ringing to query but was told 'be patient and all appointments will be rescheduled'"* – ***57 year old female with gastrointestinal cancer, Yorkshire and Humberside, England***

Last minute cancellations or not being informed of cancellations meant some people attended the hospital for their testing appointment but were sent away. Linked to this were errors on the system, such as forgotten appointments and the failure to book appointments.

> *"Doctors wanted monthly appointments to check on wound healing and lymphadenopathy, hospital appointments failed to book them had to chase appointments up, also messed up on scan/biopsy of lymphadenopathy."* – ***66 year old male with head or neck cancer, East Midlands, England***

> *"I was originally due to have an endoscopy and another throat investigation...I was sitting in the admissions lounge in my hospital gown waiting to go down and got sent home! Along with almost every other patient there also that day. I was told I might be waiting months due to Covid, so went home unaware if I had a secondary cancer or not and in a state emotionally. Eventually I got a call to go back in in May under a private route, treated by the same NHS surgeon/consultant"* – ***50 year old male with lung cancer, London, England***

A lack of communication within the health system was also reported, with patients finding consultants were unaware of the status of their tests or changes to testing that had been made.

> *"My scan was postponed by the hospital, I was told but my consultant wasn't. When my consultant contacted me to discuss my results. I informed him that my scan had been postponed by the hospital, he then arranged for a scan to be taken, which it was duly done."* – ***57 year old male with genitourinary cancer, Scotland***

For many this lack of communication had a significant emotional impact, leaving several patients feeling forgotten or abandoned. This also removed emotional and practical support for some patients as they were unable to ask questions or seek further information.

> *"First year follow up mammogram and consultation due June - no appointment came. Had to chase it up . Had mammogram done and results sent in letter @ 4 weeks later- too long. Didn't even have phone call follow up to see how I was doing. Feel abandoned and disappointed."* – ***55 year old female with breast cancer, Wales***

Remote testing

Many reported a switch from face to face assessments to remote consultations. For some patients, instruction on how to self-check was given over the phone, as well as being asked to email photos of concerning symptoms to the GP. For others, a direct alternative could not be offered, for example one cancer patient reported having their x-ray changed to a remote phone consultation.

> *"…Nurse…[follow up] for melanoma should be full physical exam with magnifying*

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[14] Abdominal perineal resection surgery

> *glass. My husband was asked to do this with nurse on the phone at home. Skin [department]… has now got a dedicated email address for patients sending in photos of worrying lesions, which was useful. When I sent in a photo I was invited to a face to face appt at the hospital and had a biopsy. My next review is early March and I do not know if this will be on the phone or face to face." –* ***69 year old female with multiple cancer types, South West, England***

A move to remote testing, such as remote blood tests, was less common, but reported. This often involved a health care professional, such as a nurse, attending the patients' home to assist. The cancellation of follow up appointments was also reported, in line with a trend of only necessary in-person appointments being made available. This often involved testing or treatment taking place in a hospital setting without a follow up with their usual doctor or consultant.

> *"I had to chase it up and although had my first year mammogram did not have follow up appointment, not even a phone call to see how I was doing - just a letter saying mammogram results were ok" –* ***67 year old female with breast cancer, South West, England***
>
> *"I have not yet had a DEXA bone scan and have not been told when or if I will have one. I recently had my 1st year mammogram but was told that I would not be having a follow up with my surgeon due to COVID but I have requested to speak to my surgeon who I have not seen since my diagnosis" –* ***57 year old female with breast cancer, Wales***

Private testing

Many patients reported having their testing moved to private hospitals. Most commonly this was initiated by the patient in the wake of delays or cancellations, but this was sometimes organised by the NHS. For a small number of people this led to a sense of losing trust in the NHS.

> ***"…****Rang letter to check COVID restrictions told not to come no appointment waiting for me, I had been counting down from November I asked for a number to ring given eye hospital number. Rang my surgery to complain. They had got letter to say I should go nothing after. I asked secretary to check no one else turns up. I apparently had been dropped of list. I am now unable to trust NHS I am paying privately I have to have 2 or 3 operations I need plastic surgery to cover the damage. I will now be out of pocket and I am a pensioner who worked for the nhs for 30+ years." –* ***74 year old female with multiple cancer types, West Midlands, England***

Primary and secondary care disputes

Most people were unaware or did not provide a reason as to why there were changes to their testing. For those who did provide a rationale, the majority attributed this to the general impact of Covid-19. However, a number of patients reported barriers to obtaining appropriate tests between primary and secondary care, either with GPs requesting tests in hospital settings and struggling to secure appointments or for a few patient's consultants requesting tests in primary care and facing barriers[15]. In a minority of cases patients, reported active

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[15] Barriers were broad and included GPs not approving requested tests

disputes between primary and secondary care teams about whether testing could go ahead.

> *"…My consultant sent my GP the forms so I could have blood tests locally at a non covid hospital but the GP refused to mark the forms as urgent so the hospital wouldn't do the tests although the person answering the phone at the hospital said cancer tests should have been marked urgent. So the next time my bloods were due (overdue!) in the second lockdown (England), …eventually got the right tests at my usual hospital." –* ***57 year old non-binary cancer patient with blood cancer, London, England***

Lower risk

As well as relationships between primary and secondary care, another reason reported by patients for delays, cancellations and changes to testing was being at a lower risk, either because their cancer was more stable, or their symptoms indicated being at a lower risk of having cancer. This left a small number of patients feeling their symptoms were not taken seriously and sometimes resulting in a later diagnosis.

> *"When I found out my thyroid ultrasound was cancelled, despite having had positive uptake on a PET scan, and both the respiratory consultant and my GP requesting an ultrasound…I arranged to have a private ultrasound…The sonographer advised me to seek specialist advice as the nodule was suspicious. Again, my GP tried to arrange for a FNA[16]…but I was turned down again…I had a call…to say that over 90% of thyroid nodules were benign and even if mine was malignant, thyroid cancer is very slow growing and so it would be quite acceptable to wait until after Covid…I referred myself as a private patient (self funding)...I had a hemi-thyroidectomy…and was informed by phone…that they had found papillary thyroid cancer…" –* ***57 year old female with head or neck cancer, South East, England***

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[16] Fine Needle Aspiration Biopsy of Thyroid nodules

4.2 Impact on Treatment

Of the total sample, 456 cancer patients were due to have treatment since March 23rd 2020. Of this group 24 reported they were due to have or had received their treatment as part of a clinical trial.

The most common reason cancer patients gave for their treatment was to completely remove the cancer from their body or kill all cancer cells (primary treatment). The next most common reason was palliative treatment (to relieve side effects). The most common single treatment reported to be due was chemotherapy, followed by surgery. However, the most reported treatment involved multiple treatment types[17].

Of the 477 cancer patients who were due treatment since the start of the pandemic (March 23rd 2020), 71% stated that their treatment had continued as expected[18] (n = 323), **29% said that their treatment has been impacted in at least one way**[19] (n=133).

4.2.1 Demographic differences

National and regional differences

There were no significant differences in those impacted by UK nation[20] or region in England[21]. See tables 5- 8 appendix 1 for demographic details on devolved nations and table 3 below for proportion impacted across UK nations.

Table 3: Proportion impacted across UK nations

Nation	Total sample (unweighted)	Proportion Impacted
Wales	N = 53	42%
Scotland	N = 73	36%
England	N = 744	29%
Northern Ireland	N = 25	16%

Gender, social grade and age

There were no significant differences by gender[22], social grade[23], or age[24].

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[17] 'Multiple treatment types' is a composite variable of anyone who said they were due more than one treatment type since March 23rd 2020.

[18] less than 1% chose not to have treatment due to COVID-19 (n = 2) or for another reason (n=1) suggesting similar trends to testing that most people did not choose to have their tests or treatment delayed or cancelled themselves. Those who chose not to have treatment were not included in the 'impacted' variable above.

[19] This is a composite variable, and impacted includes cancellations, delays or changes to their planned treatment.

[20] Nation: Pearson's Chi-square, p = .223

[21] Region: pearson's Chi square, p = .103

[22] Gender: Fisher's exact Chi-square, p = .212

[23] SES: Fisher's exact Chi-square, p = .756

[24] Age: Pearson's correlation, p = .504

Cancer Stage

There were significant differences by cancer stage at diagnosis[25,26]. The stage at which patients reported the highest rates of impact was stage 2, and the least stage 3 with a 12%-point difference. See table 4 for findings.

Table 4: Proportion of cancer patients reported testing impacted by stage

	N	Proportion Impacted
Stage 1	83	25%
Stage 2	120	34%
Stage 3	104	22%
Stage 4	96	30%

4.2.2 Waiting Times

Of the 133 cancer patients who indicated their treatment had been impacted, those who indicated they had experienced a delay or cancellation were asked how long in weeks they had to wait to be seen (n=81). **The average number of weeks delay was 13.5 weeks** (IQR: 25th 5.26 weeks; 50th 8 weeks; 75th 16 weeks).

4.2.3 Clinical Trials[27]

24 cancer patients reported that they were receiving their treatment as part of a clinical trial (n=19 from England, n= 4 from Scotland and n = 1 from Northern Ireland). The majority of those on clinical trials reported that their treatment had stayed the same (71%), but some experienced changes to treatment (8%) including being moved to standard care (4%). Only one participant reported that they were not moved to standard care following a clinical trial becoming unavailable. See table 5 for a breakdown.

Table 5: number and proportion of cancer patients who were receiving their treatment as part of a clinical trial, self-reported impact.

Number of patients	Proportion of patients
I was previously offered a clinical trial, but it was no longer available.	0%
I was on a clinical trial receiving treatment, but this was no longer available, and I received standard care instead.	4%
I was on a clinical trial receiving treatment, but this was no longer available, and I did NOT receive any standard care instead	4%
I was previously offered a clinical trial but chose not to take part due to covid-19	0%

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[25] Cancer stage at diagnosis, including those who did not know, or reported they prefer not to say: Pearson's Chi-square, *p* = .003

[26] Cancer type and treatment type were not studied further for statistically significant relationships in relation to treatment impact as there was too smaller base samples sizes within some groups and multiple comparisons weakening statistical power, however descriptive stats are provided in appendix 3

[27] This section on clinical trials includes small sample sizes and unweighted data.

I was offered to participate in a clinical trial but chose not to take part for another reason	0%
I am on a clinical trial, but the trial had to change	8%
I am on a clinical trial, and the trial stayed the same	71%
Not applicable	17%
Prefer not to say	0%

4.2.4 Qualitative analysis of treatment experience data

A total of 631 open text comments were provided by cancer patients in response to nine questions about the impact COVID-19 had on them and their treatment. Of these 613 comments were from patients whose treatment had been impacted. A further 18 comments were then analysed from patients who had experienced no changes to testing to ensure all experiences were considered to address the research questions. These comments were analysed thematically to understand the experiences of cancer patients. This analysis was grouped into **three themes and five sub themes: 'cancellation & delays' (with sub themes of: 'cancer surgery and supportive treatment', 'lack of communication', 'cancellation threats' & 'private treatment'), 'treatment plan alteration' (with sub themes of 'intensity' & 'switch') and 'personal safety & low risk'.**

Cancellations & delays

The most frequently reported change to patients' treatment was a mixture of both cancellations and delays.

(i) Cancer surgery and supportive treatments

Both surgery and non-life saving treatment to repair, improve or maintain health, such as physiotherapy and reconstructive surgery, were the treatments most heavily affected by cancellations or long delays.

Surgery appeared to be acutely affected by widespread cancellations rather than cancellations on the basis of personal risk which were perceived to drive cancellations and delays in other treatment types. A number of patients felt Covid-19 was being prioritised over cancer, leaving them feeling worried and forgotten.

> ***"…****I have been shocked by how cancer patients have been neglected during the pandemic…There will be patients who suffer needlessly because the NHS appears to have forgotten cancer exists." –* ***47 year old female with breast cancer, South East, England***

Patients reported uncertainty around the status of their surgery, with last minute cancellations being common and some patients unclear whether their surgery would go ahead up until the day of their expected treatment. It was also common for parts of surgery to be delayed, particularly non-curative surgery, such as reconstructive surgery, with cancer surgery still going ahead without the planned reconstruction.

> "…The day before I was told there were no beds but to turn up for surgery and hope. On the day the surgeon told me if no beds I would have to endure a mastectomy and hope for reconstruction at a later date…I was devastated. Half an hour before surgery a bed became available and my full surgery went ahead. I still suffer with memories of

> that.” – ***39 year old female with breast cancer, North East, England***

(ii) Lack of communication

Patients reported needing to repeatedly contact hospitals for appointments, having appointments forgotten or missing from the system and lacking information on the status of their treatment. Patients reported a significant emotional impact of this uncertainty, with a sense of feeling forgotten being common. The emotional impact of this uncertainty was sometimes greater than the impact of changes to treatment.

> *“It was just the not knowing what was happening. Could not get hold of any one to keep me updated on what was happening” –* ***61 year old female with multiple cancer types, East Midlands, England***

> *“I felt abandoned and in the dark” –* ***47 year old female with breast cancer, North West, England***

> *“They didn't have any info to give... felt abandoned.” –* ***44 year old female with breast cancer, East Midlands, England***

(iii) Cancellation threats & private treatment

A small number of patients reported experiencing the threat of cancellation to their treatment and having to advocate to receive their planned treatment. These potential cancellations largely arose due to the risk of exposure to Covid-19 by being in hospital for treatment. This led to a lot of uncertainty and fear.

> “…When i discussed adjuvant chemotherapy for my cancer the oncologist told me that the real risk was becoming so ill during chemotherapy that I needed inpatient care but there not being a bed for me because they would be overwhelmed with Covid-19 patients I had to advocate for my own treatment in order to increase my long term prognosis whilst being added to feel that if I chose this treatment they wont be able to look after me. Its sheer terror. Cancer in this pandemic is sheer terror. I'm 39 and a single mother of 3 small children. I must be around to guide them as they grow. This is the only reason I found the strength to advocate for myself to get the treatment that prior to the pandemic would have been granted without batting an eye.” – ***39 year old female with breast cancer, North East, England***

Where patients were unable to receive the full treatment they expected, a small number of patients explored getting treatment in private clinics. This was often driven by feelings of frustration and concern for the status of their cancer.

> *“I was initially told that I would have surgery within 4 to 6 weeks. I was then given a marena coil as an interim measure and told that surgery was going to be delayed by as much as 6 months. I had an online appointment with an anaesthetist and was then told they had no idea when the surgery would take place. I felt that I was then forgotten about entirely as there was no more contact for many weeks. I eventually took matters into my own hands and managed to find a private doctor in England, I’m in wales, who was prepared to carry out my surgery.” –* ***56 year old female with gynaecological cancer, Wales***

Treatment plan alteration

(i) Intensity

Where there were changes to treatment plans, a switch to less intensive treatment was more common than a switch to more intensive treatment. Moving to a shorter dose or having components of treatments removed was common. This was most frequently observed for patients undergoing chemotherapy and radiotherapy. Patients perceived the reasons for these changes to be related to both their own safety, in reducing exposure to Covid-19 by undergoing treatment in hospital, as well as an overloaded system due to Covid-19.

> "…My chemotherapy continued but at a reduced dosage. My chemotherapy did not result in a complete pathological response and I now have further treatment which I do wonder might not have happened with the full dosage." – ***36 year old female with breast cancer, South East, England***

Although less common, a move to more intensive treatment also emerged within this theme. This was thought to be for the personal safety of patients, as by having shorter but higher doses of treatment there was a reduction in time in hospital and so exposure to Covid-19. There were also a few instances in which delays to treatment had a knock-on effect of requiring more intensive, additional or modified treatment.

> "Concurrent chemo and radiotherapy was condensed into a three week programme of higher dose instead of 6 weeks. Following programme of 6 chemo sessions remained the same"– ***67 year old male with cancer of the central nervous system, brain, eye, East Midlands, England***

(ii) Switch

Patients who were due to have surgery reported a switch in their treatment plan to hormone therapy, most commonly for a limited period of time while waiting for delays to surgery to ease. This is consistent with themes mentioned above, with surgery reported to be particularly affected by widespread cancellations and delays.

> "Possible surgical option to remove prostate but unlikely I could be offered this until later in 2021 due to pressure and other priorities on services. Have commenced hormone therapy treatment in meantime." – ***61 year old male with genitourinary cancer, London, England***

A move from face to face care to remote delivery for parts of patients' treatment plans was another commonly reported theme. This was primarily seen for consultations rather than treatment.

Personal safety & low risk

Most patients perceived that changes to treatment resulted from the general impact of Covid-19. These were primarily systemic factors such as widespread cancellations or hospitals being overwhelmed.

However, individual factors were also reported as reasons for changes to treatment. Firstly, concerns over a patient's personal safety, in being exposed to Covid-19 by entering a hospital led to changes such as increasing the intensity of treatment to reduce time in hospital or even removing parts of treatment plans. This was particularly common for patients undergoing chemotherapy. Secondly, a small number of patients perceived their low risk (such as the slow progression of their cancer or the fact their cancer was stable) as a factor in changes to their treatment plan. Cancellations or delays appeared to be the most common change in treatment for this group.

> *"…My chemo stopped because they thought the risk of catching covid at hospital was too high and I wouldn't survive it if I caught it." –* ***73 year old female with gynaecological cancer, Northern Ireland***
>
> *"My test results did not change during the period of waiting, so there was no need to start treatment immediately. I started treatment as soon as the Trial opened. and I have responded well to treatment" –* ***79 year old male with blood cancer, South West, England***

4.3 Impact on Care

The total sample were asked, aside from their tests and treatment, what they had experienced since the start of the pandemic that might have impacted their overall care. **80% reported at least one impact.** The most reported impact to their care was going for treatment alone, followed by cancellations and postponements to check-ups. See table 6 for summary of the results.

Table 6: summary of cancer patients' experiences of their care since the start of the pandemic.

Type of care	proportion who experienced this impact to their care
Going for treatment on my own	64%
Check-ups at hospital cancelled or postponed	32%
Can't meet support group (cancelled, postponed or too difficult to access)	24%
Less support from a clinical nurse specialist (e.g. palliative care, breast care nurse or haematology nurse).	20%
Less regular communication from my doctor or nurse	20%
Lack of information from my doctor or nurse	12%
Less supportive care in general (such as less palliative treatment)	9%
Physiotherapy cancelled or postponed	7%
Reconstructive surgery cancelled or postponed such as breast reconstruction, reversal of stoma, etc.	7%
Other	5%
Other rehabilitative treatment/care cancelled or postponed	4%

Below are a few comments from those who took part in the survey about their care:

> *"Face to face appointments for hair loss and for prostheses not available. Felt very unsupported after my mastectomy."* – **Female aged 56 with breast cancer, South East, England**
>
> *"being told you have cancer on your own"* – **Female aged 67 with genitourinary cancer, South West, England**
>
> *"No specialist prosthesis fitting"* – **Female aged 57 with breast cancer, Northern Ireland**
>
> *"Difficulty with jab and chemo dates"* – **Female aged 80 with breast cancer, North West, England**

"Feeling abandoned" – **Female aged 74 with multiple cancer types, West Midlands, England**

"delay in receiving test results" – **Female aged 51 with breast cancer, South West, England**

4.4 Overall cancer care rating

Cancer patients were also asked the rate their cancer care overall both before the pandemic started (retrospective rating) and since the pandemic started. This included testing, treatment, and supportive care (e.g. access to support groups, etc). See table 7 for responses for before the pandemic started compared to since the pandemic started. There is a 24% decrease in those reporting their care was 'very good' from before the pandemic to since the pandemic started. There is also a smaller increase in those rating their overall care as below average and average. This is similar to what we saw in the first CRUK patient survey in May 2020 (CRUK, 2020, p.18).

Table 7: cancer patients rating of the quality of their care overall before the pandemic started compared to since the pandemic started[28].

Rating of Overall care	Before the start of the pandemic	Since the start of the pandemic
Very poor	<1%	1%
Below average	<2%	10%
Average	5%	11%
Above average	10%	19%
Very good	84%	60%

Overall, 33% of the sample who provided a rating before and since the start of the pandemic downgraded their rating. Of the 84% who rated their care as 'very good' before the start of the pandemic, only 69% of them still rated their care as very good since the pandemic started, while 31% rated their care since the pandemic started as lower quality overall. See table 8 below for full breakdowns

Tables 8: cancer patients rating change since the start of the pandemic compared to before overall

	Frequency	Valid Percent
Rating stayed the same	362	65%
Rating decreased	182	33%
Rating improved	13	2%

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[28] Those who stated NA or prefer not to say were excluded from comparison to allow a comparison between waves from the perspective of those who experienced treatment both before the pandemic and after the start of the pandemic, n = 557 were included in both waves.

Tables 9: Cancer patients rating change since the start of the pandemic compared to before, by rating.

Rating	Proportion rating reduce	Proportion rating stayed the same	Proportion rating improved
Very Poor	-	100% (n=2)	0% (n=0)
Below average	29% (n=2)	71% (n=5)	0% (n=0)
Average	33% (n =9)	52% (n=14)	15% (n=4)
Above average	49% (n=25)	34% (n =18)	17% (n=9)
Very good	31% (n= 146)	69% (n=323)	-

Fahad, 29, London, England

Hodgkin Lymphoma, diagnosed 2020

“I got my cancer diagnosis over the phone - I’d specifically asked the doctors to call me with the results of my tests as I didn’t want to be going in and out of the hospital and risk getting COVID. I had always known something wasn’t right but it still came as a shock to me and my family as we have no family history of cancer and I live a healthy, active life. Since then, I’ve spent a lot of time in hospital so my family could avoid travelling back and forth during the pandemic, although that’s meant leaving my wife Shumaila with the tough job of looking after our two young children. Fortunately, my parents and brother were a huge support to her throughout. I would like to say a special thanks to the NHS who have showed me great support and care throughout my treatment.

Pat, 58, Glasgow, Scotland

Breast cancer, diagnosed 2019

“I was diagnosed through a routine mammogram and my cancer was picked up early. I started radiotherapy four days after lockdown began, and felt safe and protected thanks to the COVID protocols in place. I appreciated everything that the NHS and all the staff have been doing at such a difficult time – they were all brilliant amid all the constraints. During my treatment over the last year, I have experienced some difficulties in getting some information about results and had some delays due to COVID, but that is fair and understandable, and I appreciate that other people had to be prioritised ahead of me in the pandemic.

Sue, 53, Northamptonshire, East Midlands England

Ovarian cancer, diagnosed 2017

“I was treated with surgery and chemotherapy and I am still part of the ICON9 trial. Over the last year, my appointments with the consultant have been on the phone rather than face-to-face. I have still been going in to see my clinical trials nurse for bloods to be taken and I feel that everything is being done very safely and quickly there. I am so conscious of other patients being at earlier stages of treatment during the pandemic, and I really feel for them as it must be such a worrying time. I have been able to return to work this year but was in the shielding category initially. I have now been double vaccinated and, as I work at a hospital, we all wear full PPE and have very strict protocols to follow.

5 Experience of COVID-19 safety measures

Cancer patients generally reported positive experiences of COVID-19 safety measures, with safe spaces in hospitals for tests and treatment, wearing masks/visors and having home or community-based treatment being most commonly endorsed. Attending appointments alone was the least commonly reported positive experience and the most commonly reported negative experience (see table 10).

Table 10: proportion of cancer patients who experienced a positive or negative experience of different COVID-19 safety measures.

Safety measure	Number who experienced the safety measure[29]	Proportion who reported a positive experience	Proportion who reported a neutral experience	Proportion who reported a negative experience
'Safe spaces'	618	89%	8%	3%
Wearing masks/visors	809	80%	14%	5%
Home/community-based treatment	154	75%	16%	10%
Taking COVID-19 tests	464	74%	17%	10%
Self-isolation for an appointment	434	68%	19%	12%
Avoiding public transport	379	66%	19%	15%
Self-isolation for treatment duration	401	60%	24%	17%
Telephone calls	756	57%	24%	19%
Video calls	175	55%	28%	17%
Attending appointments alone	739	46%	21%	33%

5.1 Remote Consultations

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[29] Those who responded not applicable (that they had not experienced a safety measure), were excluded from analysis

Remote consultations were very common, with many cancer patients surveyed reporting they had experienced a remote consultation either via video (n = 175) or more commonly via telephone (n = 756). Just over one half of cancer patients surveyed felt that they were easier to do, safer to do and they felt comfortable discussing their cancer. However, about a third were worried that it might result in the wrong decision being made about their care. Just under half agreed that these could be useful to continue (after COVID-19) but around half stated explicitly they did not want to have remote consultations, and an overwhelming majority would like to choose whether their consultation is face to face/in person, or via a remote method in the future.

Positively the majority did seem to feel they had access to the equipment they needed to have their remote consultations whether that was via phone or video call, however there was still a small minority who had felt they did not have access. See table 11 for results.

Table 11: Proportion of cancer patients who selected either ‘slightly agree’ or ‘strongly agree’ (net. Agree) with each statement for both video calls and for telephone calls.

Statement	Video (Net. Agree)	Telephone (Net. Agree)
These consultations are easier for me	52%	60%
These consultations make me feel safer	63%	63%
I am concerned these consultations may result in the wrong decision being made about my care	32%	35%
These consultations could be useful to continue after COVID-19	46%	48%
I do not want remote methods for consultations after COVID-19	53%	51%
In the future, I would like to be offered the opportunity to choose whether I want a face to face consultation or remote consultation	91%	89%
I feel comfortable discussing my cancer via remote appointment	58%	66%
I had access to the equipment I needed to have a remote consultation	86%	88%

Cancer patients where then asked what they thought worked well and less well via remote methods. Palliative care, receiving a diagnosis, receiving treatment, and GP appointments for signs and symptoms all had the lowest levels of agreement for both video and telephone consultations as aspects of care which worked well remotely. There was some variation between the two methods of remote consultation but generally, things that worked well and not so well were relatively similar. See table 12 for a list of aspects of care cancer patients may need to have and the proportion of cancer patients who agreed it worked well remotely.

Table 12: Effectiveness of remote (video and telephone) consultations for different aspects of medical care

Contact type	Proportion Net. Agree works well remotely, not face to face/in person (Video)	Proportion Net. Agree works well remotely, not face to face/in person (Telephone)
Palliative care	11%	11%
Receiving a diagnosis	21%	24%
Receiving treatment	26%	24%
GP appointments for signs or symptoms	38%	42%
Discussing treatment options	50%	51%
Psychological support	52%	45%
Other health professional advice (such as Physiotherapist or a dietician, etc)	53%	54%
Follow up visits	55%	56%
Monitoring and managing of side effects	56%	60%
Receiving test results	58%	56%
Support groups	58%	48%
Social support (such as a discussion around access to benefits, etc)	60%	57%
Consenting for tests/treatment/trials	62%	63%

5.2 Home or community-based[30] treatment

Another new topic included in this survey was home or community-based treatment. 154 cancer patients reported that they had experienced home or community-based treatment since the start of the pandemic: 78% of people who experienced home or community-based treatment received this for some of their treatment, 17% reported receiving this for all of their treatment. Overall perceptions of community-based treatment were positive with many agreeing that this approach was easier, safer would be useful to continue and they would like the choice of having home or community-based treatment in the future (see table 13). Far fewer felt they would not want this type of treatment in future.

Table 13: Proportion of cancer patients who selected either 'slightly agree' or 'strongly agree' (net. agreed) with statements about their home or community-based treatment.

Statement	Proportion net. agree

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[30] At home or locally at a GP's office for example

In the future, I would like to be offered the opportunity to choose whether I want hospital-based treatment, home-based treatment or community-based treatment.	91%
Home or community-based treatments are easier for me	75%
Home or community-based treatments could be useful to continue after COVID-19	74%
Home or community-based treatments make me feel safer	69%
I do not want home or community-based methods of treatment after COVID-19	20%

6 Wellbeing

6.1 Worries and Concerns

All cancer patients (N=900) were asked about their worries and concerns from Dec 2020 - March 2021. They remained similar to what we saw in May 2020 (CRUK, 2020, p.22) with around half of cancer patients reporting concerns about becoming seriously ill from COVID-19 and catching COVID-19. Over one third were concerned about future plans and isolation/loneliness. See table 14 for the full list of concerns.

Table 14: number and proportion of concerns and worries reported by cancer patients, listed from highest endorsed to lowest endorsed.

Concern	Proportion
Becoming seriously ill from COVID-19	50%
Catching COVID-19	49%
Future plans	37%
Isolation/loneliness	36%
Friends or family living outside your household	32%
Attending hospital appointments during the pandemic	24%
Work (even if you feel your job is safe)	23%
The impact lockdown is having on my cancer treatment and care	22%
Finances	21%
Brexit	19%
Dying alone	17%
Your own safety / security	16%
Other COVID-19 restrictions	14%
Getting medication	12%
Losing your job / unemployment	11%
None of these	11%
Getting food	10%
Friends or family living in your household	10%
Marriage or other romantic relationship	9%
Other, please specify:	8%
Current funeral restrictions	4%
Prefer not to say	<1%

6.2 Emotional Impact

All cancer patients who took part in the survey (N=900) were asked how they had been feeling since the start of the pandemic, identifying what emotions they had been feeling more, less or the same amount. Similar to our previous survey in May 2020 (CRUK, 2020, p.21), 'frustrated' and 'anxious' were still the most common emotions being felt 'more since the start of the pandemic. See table 15 for full emotions reported to be experienced 'more' since the start of the pandemic[31].

Table 15: full table of emotions reported by cancer patients to be felt 'more' since the start of the pandemic. Listed from highest to lowest.

Emotion	Proportion feeling this more	Proportion feeling this the same amount	Proportion feeling this less
Frustrated	67%	30%	2%
Anxious	62%	35%	2%
Upset	50%	45%	3%
Afraid	47%	49%	3%
Overwhelmed	46%	47%	5%
Helpless	45%	49%	4%
Alone	39%	53%	6%
Hopeless	31%	60%	6%
Optimistic	6%	39%	54%
Safe	5%	42%	51%
Confident	4%	44%	50%
Satisfied	4%	44%	50%

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[31] Although this metrics did not give a scale of how much frustration or anxiety was felt e.g. low, medium or high, the purpose of this question is to give an indication for everyone of whether things were intensified by the pandemic, stayed the same or were reduced.

7 Government actions

All cancer patients were asked which government actions they endorsed. By far the most endorsed government actions were to ensure patients with symptoms can be tested in a timely manner (94%) and ensuring adequate capacity to address the backlog of cancer patients (92%). See table 16 for a full list of government actions and cancer patients' support for them.

Table 16: Government actions and cancer patients support, listed from highest to lowest.

Government actions	Proportion endorsing action
Ensure that patients who have potential symptoms of cancer can be tested in a timely manner	94%
Ensure adequate capacity for cancer services to tackle the backlog of patients waiting for screening, diagnosis and treatment as quickly as possible	92%
Offer a safe environment, such as a COVID-19 free zone, for cancer patients to be treated	90%
Support the restart of non-COVID research (including cancer research)	83%
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)	82%
Revise cancer workforce plans to ensure diagnostic and treatment services can meet growing future demand	77%
Ensure that public health services are fully resourced	75%
Ensure 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	71%
Improve messaging to the public that the NHS is still open and encourage them to seek help	70%
Ensure smokers have universal access to stop smoking services to help them quit	43%
Introduce legislation to stop all junk food advertising online	34%
Introduce legislation to stop junk food advertising on TV before 9pm	33%
Other, please specify:	4%
Prefer not to say	0%

8 Discussion

8.1 Summary of findings

Although the proportion of patients reporting a negative impact of COVID-19 on testing, treatment and care appears to have slightly reduced since our first survey, just over 1 in 3 cancer patients in the UK still reported a delay, cancellation or change to their expected tests, and just under 1 in 3 reported a delay, cancellation or change to their expected treatment, with an average wait time of 13.4 weeks for testing and 13.5 weeks for treatment.

Patients also still had concerns about catching or becoming seriously ill with COVID-19, a key theme in the last survey. In addition, around 1 in 3 patients reported again that they felt more frustration and anxiety since the start of the pandemic, indicative of the additional burden the pandemic is having on the lives of cancer patients.

Findings relating to cancer patients' experience of COVID-19 safety measures suggest many are appreciative of the additional measures and reported mostly positive experiences for many of these. There are, however, those who did have negative experiences of some safety measures, with around 1 in 3 (33%) reporting a negative experience of attending appointments alone. Findings relating to when remote consultations have worked well or less well could be used to support clinicians to know when remote measures are suitable and when face to face consultations are needed for greater patient benefit (CRUK, 2021).

This survey has generated findings from a sample of cancer patients, which have painted a more detailed picture of how the lives of the tens of thousands of patients that may have been impacted since the start of the pandemic. Patients whose tests have been cancelled, people whose treatment has been delayed, lives that have been changed forever.

8.2 Recommendations

This report offers a stark snapshot of the devastating impact of the COVID-19 pandemic, and its knock-on impact on cancer services. Cancer patients, having lived through the pandemic's significant disruption to their own care with delays, alterations and cancellations to diagnosis and treatment, clearly now expect governments across the UK to take decisive action to address the impact of COVID-19.

The significant disruption to diagnostic tests and cancer treatment that CRUK's cancer patient experience survey in May 2020 captured have persisted into 2021 and the subsequent waves of the pandemic. For patients, delays, alterations or cancellations to diagnostic testing and cancer treatment not only may have contributed to the increase in frustration and anxiety during their cancer care, but could also negatively affect outcomes. While many services have now largely recovered to around pre-pandemic levels, to address the impact of the pandemic and ensure timely diagnosis and treatment for all cancer patients will now require a significant ramping up of activity.

- Governments must maintain financial resources to address the impact of the pandemic and increase capacity in primary care, screening, diagnostic and treatment services.

The report also reflects some improvements from when the pandemic first started. This suggests changes to NHS service delivery to improve resilience may have made a tangible difference for patients. In coming months, it is inevitable that significant pressures will continue to exist across the UK's health systems, with services required to address the growing backlog in elective care as well as respond to any subsequent waves of COVID-19 cases.

- Governments and health systems must continue to protect cancer services, learning the lessons of the last year to ensure that no cancer patients face further disruption.

However, the barriers to timely cancer diagnosis and treatment identified by people affected by cancer in this report are not a phenomenon that have emerged only in the pandemic. Even before COVID-19, cancer services were on the verge of crisis, with cancer waiting time targets routinely missed and progress to improve cancer survival lagging behind comparable countries. A fundamental factor driving this has been years of underinvestment and lack of strategic direction in growing capacity in increasingly stretched cancer services, and the vast majority of patients surveyed supported governments taking steps to ensure that there is enough staff in diagnostic and treatment services to meet growing future demand. Significant investment will be required to make expanding capacity in cancer services a reality.

- In the upcoming 2021 Spending Review, the UK Government must provide substantial investment in order to deliver a multi-year funding settlement, mirrored in each devolved nation, to invest in more training places for key specialties for diagnosing and treating cancer.

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Appendix 1

Table 1: Proportion of cancer patients at each stage in the NHS cancer pathway, ordered chronologically[32].

Cancer Patient point in NHS cancer pathway	Proportion
I am experiencing potential signs or symptoms of cancer, but not received a diagnosis	1%
I have received an abnormal result from a cancer screening test, but have not received a final diagnosis	<1%
I have been referred for suspected cancer, and I am either waiting for a test or results to get my diagnosis	<1%
I was recently diagnosed with cancer, but I have not yet started treatment	5%
I am currently undergoing treatment for cancer	42%
My cancer treatment has finished, but I am still being monitored	37%
My cancer treatment has finished, and I do not need further monitoring	2%
I am living with terminal cancer and not having treatment	2%
I am living with terminal cancer and having treatment	5%
I am living with terminal cancer and receiving palliative care	<1%
I am in remission and have been for less than 5 years	2%
I am in remission and have been for more than 5 years	1%
I don’t know	<1%
Prefer not to say	<1%

Table 2: Proportion of different cancer types, listed highest to lowest.

Cancer Type	Proportion
Breast	25%
Blood (including leukaemia, lymphoma, Hodgkin and Non-Hodgkin lymphoma, multiple myeloma)	16%
Genitourinary (including bladder, kidney, prostate, testicular)	15%
Multiple cancer types	13%
Gastrointestinal (including colon, rectal, anal, stomach, intestinal, oesophageal)	12%
Genitourinary (including bladder, kidney, prostate, testicular)	15%
Gynaecological (including uterine, cervical, ovarian, vaginal, vulvar)	6%
Lung	4%
Head or neck (including mouth, throat, tongue, nasal)	3%
Skin cancer (melanoma and non-melanoma)	2%
Sarcoma (including soft tissue, osteosarcoma)	2%

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[32] Pink text indicates where in the pathway most patients who took part in this survey were.

Central nervous system, brain, eye	2%
Endocrine	<1%
Hepatobiliary (including pancreas, liver, biliary)	<1%
Not supplied	<1%

Table 3: Proportion of different cancer stages, listed in order of stage.

Cancer Stage	**Proportion**
Stage 1	20%
Stage 2	27%
Stage 3	24%
Stage 4	18%

Table 4: Timing of cancer diagnosis, listed chronologically.

When were they diagnosed	**Proportion**
Before March 23rd 2020	64%
March 23rd - July 4th 2020	8%
July 5th-September 21st 2020	10%
September 22nd 2020 to March 30th 2021	18%
Waiting for diagnosis (2021)	<1%
Prefer not to say	<1%
Not supplied	<1%

Table 5: Region sample sizes from Scotland

	Number	**Proportion in Scottish sample**
Greater Glasgow and Clyde	22	30%
Lothian	11	15%
Lanarkshire	10	14%
Tayside	7	10%
Grampian	5	7%
Forth Valley	4	5%
Ayrshire and Arran	4	5%
Dumfries and Galloway	3	4%
Highland	2	3%
Fife	2	3%
Borders	2	3%
Eileanan Siar Western Isles	1	1%
Total	73	100%

Table 6: Region sample sizes from Wales

	Number	Proportion in Welsh sample
Betsi Cadwaladr University Health Board	14	26%
Cardiff & Vale University Health Board	12	23%
Aneurin Bevan Health Board	8	15%
Powys Teaching Health Board	6	11%
Swansea Bay University Health Board	4	8%
Hywel Dda Health Board	4	8%
Cwm Taf Morgannwg Health Board	3	6%
Prefer not to say	2	4%
Total	53	100%

Table 7: Region sample sizes from Northern Ireland

	Number	Proportion of Northern Irish sample
Southern	6	24%
Northern	6	24%
Belfast	4	16%
Southeast	4	16%
Western	3	12%
I don’t know	1	4%
Prefer not to say	1	4%
Total	25	100%

Table 8: Region sample sizes from England

	Number	Proportion of English sample
South East	178	24%
North West	105	14%
East Anglia	81	11%
London	76	10%
South West	77	10%
West Midlands	70	9%
East Midlands	70	9%
Yorkshire and Humberside	53	7%

North East	31	4%
Prefer not to say	3	<1%
Total	744	100%