

Blood  
cancer  
UK



**The impact of  
Covid-19 on people  
with blood cancer**

# Contents

|                                |    |
|--------------------------------|----|
| Introduction                   | 3  |
| Headline findings              | 4  |
| Our recommendations            | 5  |
| Policy timeline                | 6  |
| About our survey               | 7  |
| Impact on...                   |    |
| • Mental health                | 11 |
| • Treatment and care           | 14 |
| • Work and finances            | 16 |
| • Carers                       | 17 |
| Attitudes towards shielding    | 18 |
| Our response to your responses | 21 |

# Introduction

When COVID-19 first spread across the UK in March 2020, there was little information or support for individuals with blood cancer but a great deal of fear and uncertainty. This fear was well-founded: compared with other cancer types, people with blood cancer are the most vulnerable to COVID-19. To understand and address these challenges, we carried out a survey of people affected by blood cancer on COVID-19.

With over 6,400 responses from patients and carers across the UK, we learned of severe anxieties within the blood cancer community; the impact the pandemic was having on people's mental health, appointments, and treatment; persistent issues with Government / NHS letters advising vulnerable individuals to shield; and of the various perspectives on shielding and the lockdown.

These responses have not only informed our information, support, and policy work, but also the work of others – such as clinicians, parliamentarians, and key decision-makers.

The COVID-19 situation continues to evolve. In recent weeks we have seen an increase in new cases and additional restrictions imposed on various regions across the country. Blood Cancer UK will continue to inform, support, and advocate for the blood cancer community throughout this period and beyond. To those who shared their experiences with us, thank you – your contributions have informed our work and helped us better serve the blood cancer community in this challenging time.



# Headline findings

- 1.** Our survey received **6,417** responses. **58%** of respondents have blood cancer; **23%** are in remission; and **19%** are a friend, family member, or carer of someone affected.
- 2.** Respondents' major concerns were: their risk of contracting COVID-19 (**83%**); managing shielding (**24%**); and the impact of COVID-19 on their mental health (**23%**).
- 3.** **87%** of respondents said their mental health had been impacted by the pandemic – **10%** of these respondents told us that this impact had been severe.
- 4.** **47%** of respondents said that their blood cancer appointments and treatment had been impacted in some way by the pandemic.
- 5.** **45%** of respondents with scheduled care had not been attended their appointments due to factors outside of their control; **7%** had not been attending out of choice.
- 6.** **91%** of carers said their mental health had been affected by the COVID-19 pandemic – **16%** of these carers described the impact as severe.
- 7.** **73%** of carers told us that supporting a loved one with blood cancer through the pandemic had caused them additional stress.
- 8.** Throughout the survey, **66%** of respondents with blood cancer reported having received a letter advising them to shield; **28%** told us they had not received one.
- 9.** **98%** of respondents reported following shielding guidance 'very strictly' or 'quite strictly' with most deviations for unavoidable reasons.
- 10.** **47%** of shielders told us they would be willing to shield for up to an additional six months. **22%** of shielders said they would be willing to shield indefinitely.



# Our recommendations

## Treatment and care

- The Government's message in March 2020 of 'Stay at Home. Protect the NHS. Save Lives' was effective. This message however resulted in some putting their health needs secondary to that of the health service, and to avoid seeking help even when necessary. As cases begin to rise again, we are pleased to see that the UK Governments are making efforts to **encourage people to visit their healthcare professionals** (e.g. NHS England's Help Us Help You campaign).
- Accordingly, **the NHS and hospitals must take appropriate measures to protect vulnerable patients from COVID-19** and to communicate their efforts clearly to create confidence. Regular testing of NHS staff, even those with no symptoms, will be important in this regard.
- Work to **understand the impact of COVID-19 on blood cancer treatment and care** (e.g. changes to chemotherapy and stem cell transplantation) must continue and acted upon to **restore disrupted services**.
- We have seen **rapid change and innovation across the healthcare system** such as the adoption of online consultations, greater flexibility in the management of cancer, and additional treatment options. The **efficacy of these measures should be reviewed and retained if beneficial**.



## Mental health

- Work should be undertaken to **identify the reasons some individuals lost access to mental health support** during the pandemic. This **support must resume as a matter of priority**.
- We expect the rise in demand for mental health support to continue. **The NHS and UK Governments must be ready to meet this increased demand and proactive support should be introduced**, particularly for the clinically extremely vulnerable/shielding populations.
- At particular risk of COVID-19, additional research should be performed to **assess the mental health impact of COVID-19 on the blood cancer community**.

## Shielding

- Any **changes to shielding must be communicated clearly and in advance** of implementation. As a trusted voice, **charities and patient organisations should be involved** in any messaging to ensure future guidance is clear, aligned, and available when changes are made public.
- Considering the threat of COVID-19 and initial lack of clinical data on the virus, it was right that blanket shielding guidance was first issued. As we move forward and better-understand the virus however, **a more nuanced approach should be taken** (e.g. accounting for disease type and stage of treatment).
- If shielding is reintroduced, **the shielding patients list must be kept up to date and continually reassessed** as clinical data is published. **Notifications to shield must go out in a timelier and more coordinated manner**.
- The **QCOVID risk prediction tool should be made available to the public** for individuals to better-understand their personal risk and facilitate conversations with their clinical teams.

- To ensure consistency, efforts must be taken to **improve coordination** between the devolved administrations, Government departments, and central / local Government.
- Shielding support ended in July leaving many people with blood cancer faced with the choice of protecting their health or keeping their jobs. In our **#SaveOurShielders** campaign, we called on the Government to:
  - Re-open the furlough scheme to those advised to continue shielding or where their employer could not create a COVID-free workplace.
  - Ensure those diagnosed with blood cancer were promptly added to the list of shielders.
  - Commit to the re-introduction of a full support package to those asked to shield again if the infection rate were to rise significantly.
  - Accordingly, we were pleased with the Government's decision in November to extend the furlough scheme until March 2021.

## Policy timeline (2020)

- **January 31:**  
First confirmed cases of COVID-19 in the UK.
- **March 5:**  
First COVID-19 death in the UK.
- **March 23:**  
The UK public is told that they can only leave their homes for limited reasons such as to exercise once a day or shop for groceries.
- **April 11 (week ending):**  
UK COVID-19 deaths peak.
- **May 10:**  
The Prime Minister announces the first easing of England's lockdown.
- **June 1:**  
Lockdown measures are eased.
- **June 29:**  
A local lockdown is imposed on Leicester following a spike in COVID-19 cases.
- **August 1:**  
Shielding advice for the clinically vulnerable is paused.
- **August 3:**  
The Government's 'Eat Out to Help Out' scheme is launched.
- **September 22:**  
Following a rise in the R value, new restrictions are placed on the UK including the 'Rule of Six'.
- **November 5:**  
England enters a second national lockdown, reverting to a tiered system on December 2.

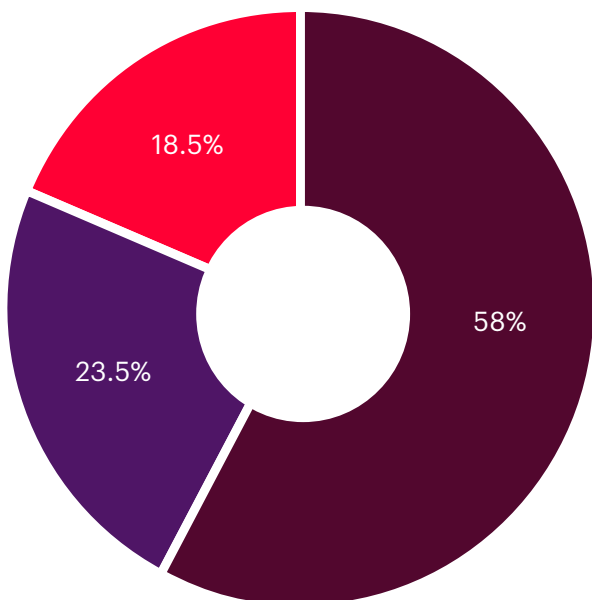
# About our survey

In March 2020, COVID-19 spread quickly across the UK. Despite their vulnerability to the virus, at the start of the pandemic there was very little information or support available for people with blood cancer on COVID-19. As such, we performed a survey to better understand the impact the pandemic was having on the blood cancer community; to gather the patient perspective; to inform our information, support, and policy work; and to inform the work of others such as clinicians, the NHS, and Government.

Although not intended to be an academic survey, the questionnaire was extensive, covering major concerns; NHS shielding letters; the impact of COVID-19 on treatment, care, and mental health; information and support needs; and an 'about you' section on the respondent. The survey also provided numerous free-text sections allowing respondents to expand on their answers and provide additional insight.

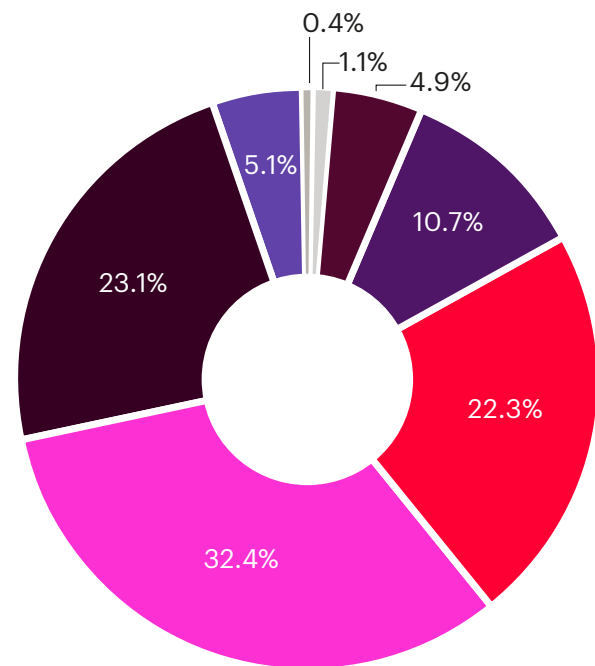
As of mid-July, the survey received **6,417** responses: **58%** have blood cancer; **23%** are in remission from blood cancer; and **19%** are a friend, family member, or carer of someone with the disease. The survey received responses from across the blood cancer community: data on gender, age, geographical location, type of blood cancer, and stage of treatment (e.g. receiving treatment, living with a chronic blood cancer, Watch and Wait, etc.) was collected. This response rate combined with the level of detail we collected on respondents means we can analyse our data in a large number of ways and the ability to ask nuanced questions. This report presents a number of our headline findings.

## Do you have blood cancer?



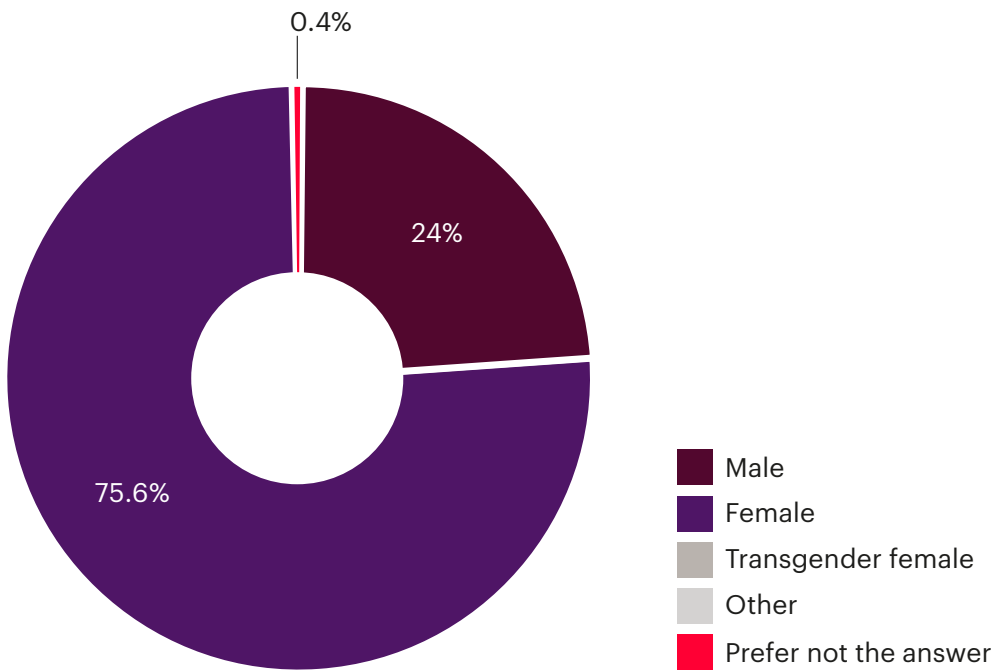
- Yes
- I am in remission from blood cancer
- No, I am a friend, family member, or carer of someone with blood cancer

## What is your age?

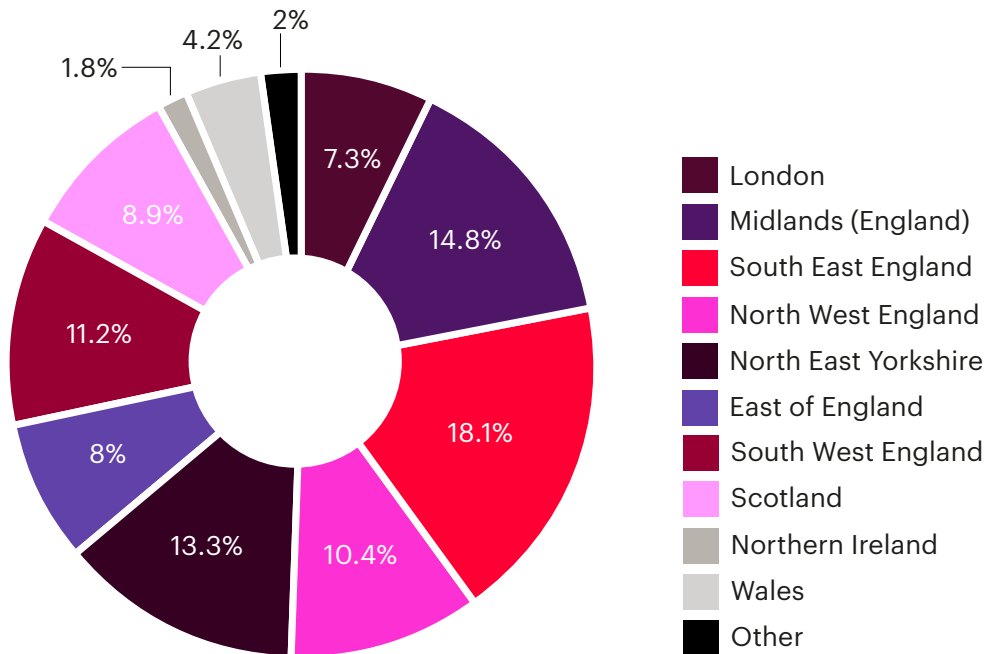


- 17 or younger
- 45 to 54
- 18 to 24
- 55 to 64
- 25 to 34
- 65 to 74
- 35 to 44
- 75 and older

## What is your gender?

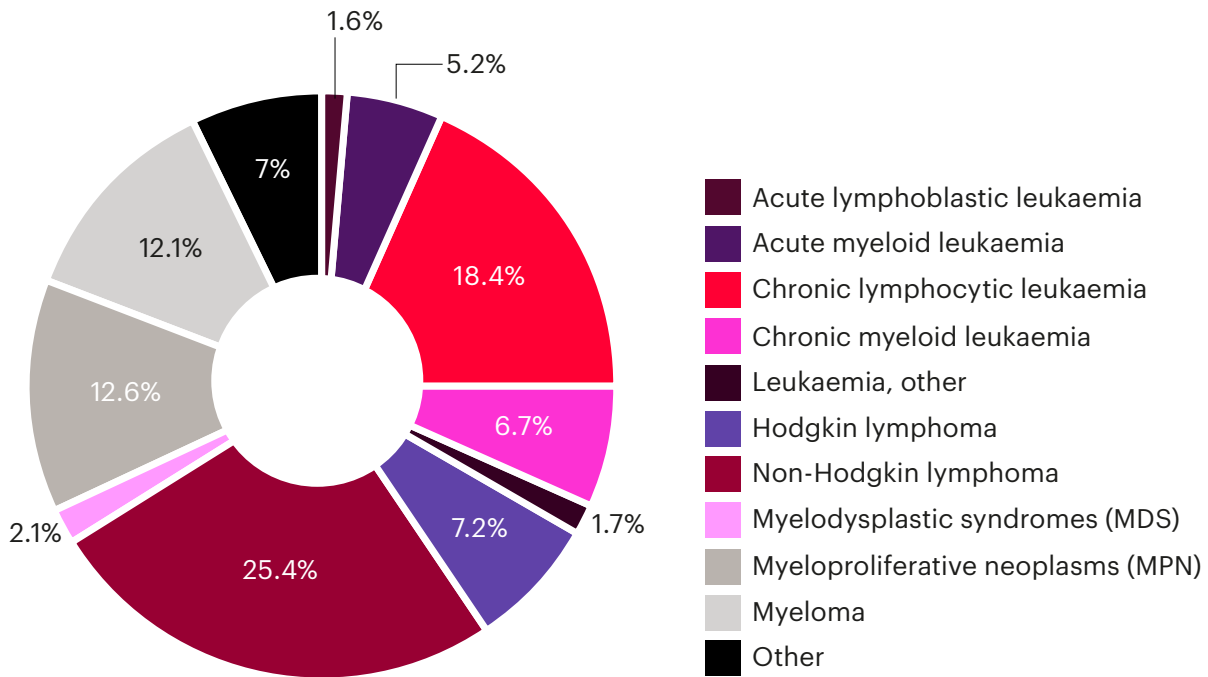


## Where do you live?

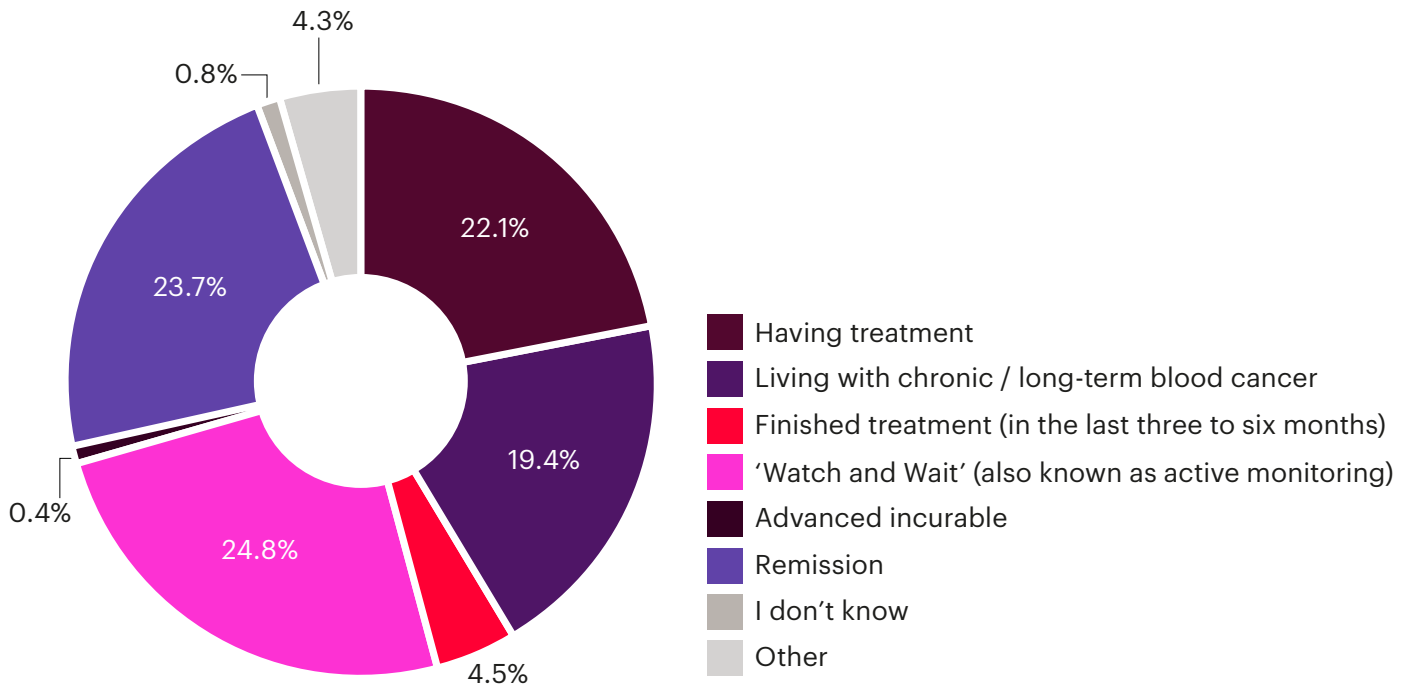




## What type of blood cancer do you / did you have?



## Which of the following best describes your current situation?



## Methodology

Our survey was launched in late March 2020, coinciding approximately with the initial lockdown restrictions and the announcement that the Prime Minister and Health Secretary had tested positive for COVID-19. We shared the survey via our channels (including our social media accounts and newsletters) and it was promoted by several other organisations. With announcements made regarding the easing of the lockdown (4 July) and the eventual end of shielding (31 July), the survey was expanded in late June to further explore the impact of COVID-19 on mental health and blood cancer medical appointments, and to determine the patient perspective of shielding and the lockdown. As the survey remained open for several months, we were able to monitor changing trends. This report examines data collected between 27 March and 13 July 2020. Anonymised patient quotes have been edited slightly for readability purposes.

## Fear and uncertainty

The major theme throughout our survey was fear and uncertainty in the blood cancer community. This is understandable: COVID-19 is a new disease and therefore poorly understood; the Government’s policies on the pandemic change regularly and are often poorly communicated; and individuals with blood cancer are more vulnerable to the disease than patients with other types of cancer.

We asked people affected by blood cancer what their major fears were about the pandemic. Throughout the duration of the survey, the respondents’ major concern was their risk of contracting the virus. Other major fears included managing social distancing and shielding, and the impact of COVID-19 on their mental health, treatment, and hospital appointments.

We added additional response options to our survey (particularly on the easing of the lockdown and the potential end to shielding) in late June to reflect changing Government guidance. Accordingly, a second wave of COVID-19 became a major concern for the blood cancer community as did the easing of the lockdown and the eventual end to shielding (see Table 1a and 1b).

| 27/03 to 22/06                        |    |
|---------------------------------------|----|
| Major concern                         | %  |
| Risk of contracting COVID-19          | 84 |
| Managing social distancing/ shielding | 25 |
| Impact on mental health               | 25 |
| Impact on treatment                   | 24 |
| Capacity of the NHS                   | 21 |
| Accessing medical appointments        | 19 |

Table 1a

| 23/06 to 13/07                        |    |
|---------------------------------------|----|
| Major concern                         | %  |
| Risk of contracting COVID-19          | 81 |
| A second wave of COVID-19             | 47 |
| Easing of the lockdown                | 25 |
| Managing social distancing/ shielding | 22 |
| Impact on mental health               | 20 |
| End of the shielding scheme           | 19 |

Table 1b

Our survey highlighted that some concerns became more or less pronounced over time: concern over the impact of COVID-19 on treatment or care for example dropped from **25%** in May to **15%** in June, and fear over the capacity of the NHS to deal with the pandemic changed from being respondents’ second largest concern in March to their eleventh in June.

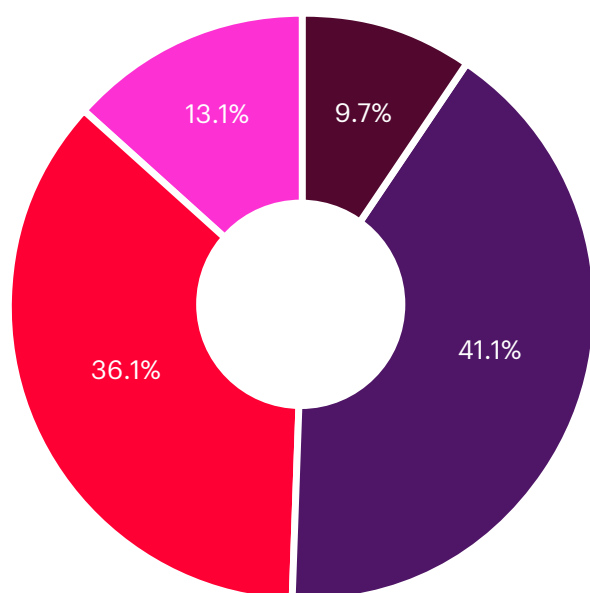
Unsurprisingly, these concerns had a major impact on the mental health of individuals with blood cancer (see ‘Impact on...Mental health’).

“ I’m panic stricken that if my husband caught COVID-19 I just wouldn’t be able to manage on my own.”

# Impact on... Mental health

Many people with cancer experience issues with their mental health. We know that there can be particular mental health challenges for those with blood cancer – primarily due to the manner in which blood cancer is diagnosed and treated.

## To what extent has coronavirus affected your overall mental health / emotional wellbeing?

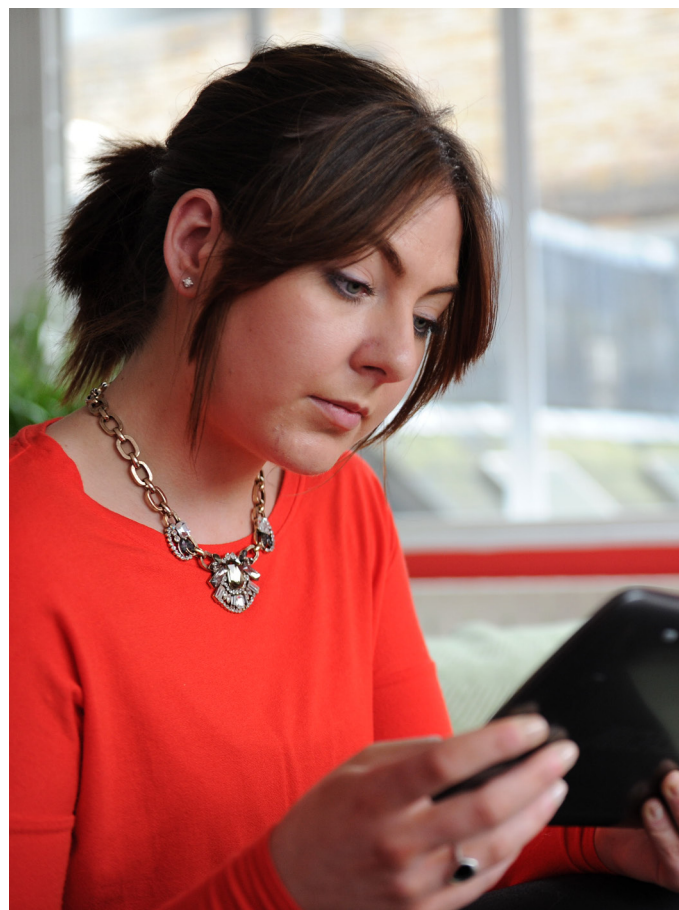


- Severely
- To some extent
- Slightly
- Not at all

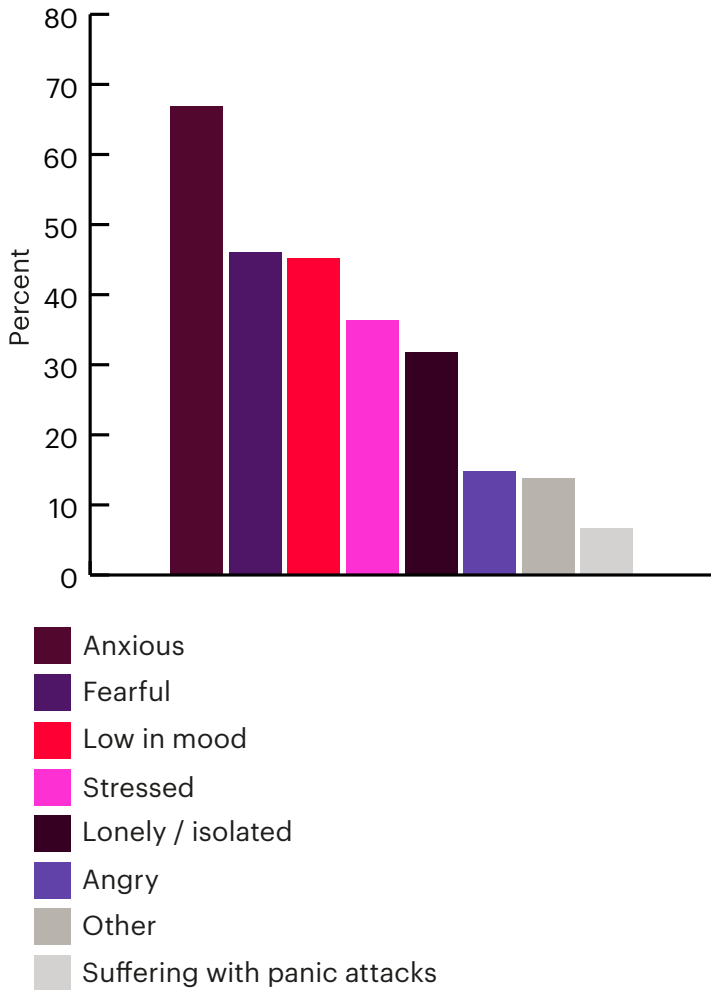
Our survey highlighted a profound mental health impact of COVID-19 on the blood cancer community. In total **87%** of respondents said their mental health had been impacted in some form by the pandemic – **10%** of respondents told us that this impact had been severe. Perhaps somewhat surprisingly, this impact remained relatively consistent week to week throughout the duration of the survey.

Respondents told us that the pandemic was making them feel anxious (**67%**), fearful (**46%**), low in mood (**45%**), stressed (**36%**), and lonely / isolated (**32%**). In terms of the impact on their day-to-day lives, respondents told us it was affecting their ability to enjoy life (**59%**), their stress / anxiety levels (**58%**), hopes for the future (**52%**), ability to carry out daily activities (**48%**), and happiness (**41%**).

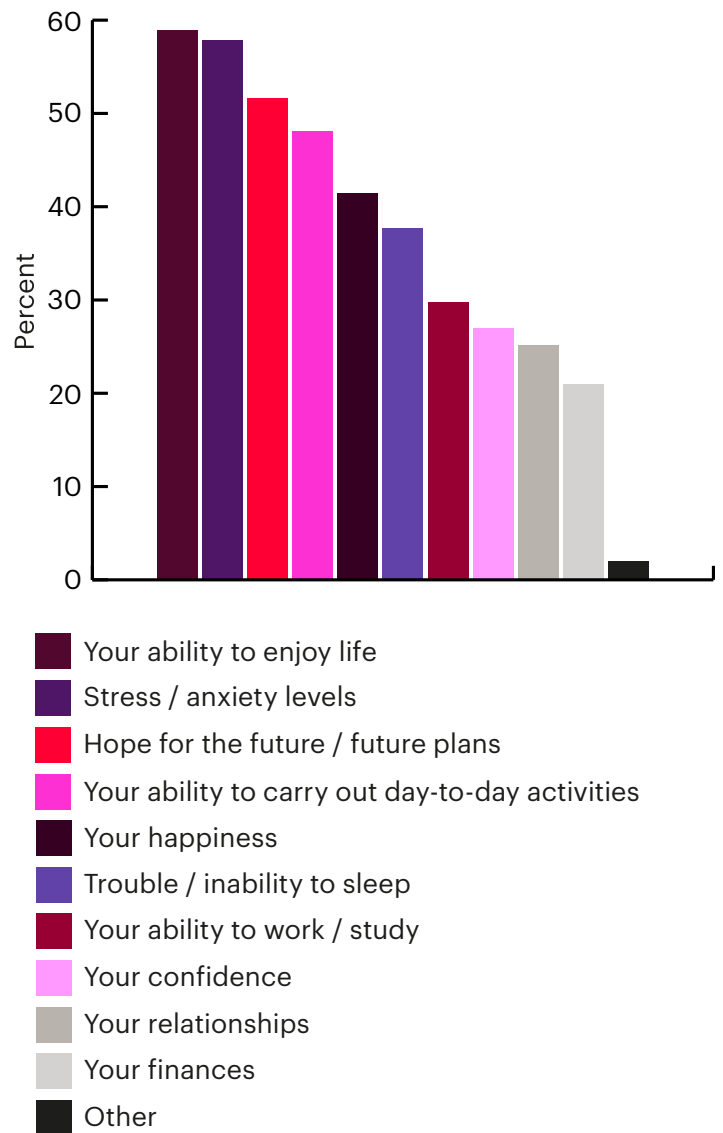
Our survey also told us that **11%** of respondents had been accessing professional support for their mental health prior to the pandemic. Worryingly, despite an increased need for mental health support, **32%** of these respondents reported having lost access to this support. We do not yet understand the reason for this.



## How has the coronavirus pandemic made you feel?



## Has the coronavirus pandemic affected you in any of the following ways?



While important, we know that shielding from other people (in particular friends and family members) was deeply challenging for the vulnerable community. Our survey highlighted that many in this category sought mental health support due to the difficulties associated with the measure. **14%** of shielders had spoken to their friends and family members about their mental health struggles, while **4%** and **3%** of respondents had contacted their GP or a mental health professional respectively during the pandemic regarding their mental health.

The latter two percentages are surprisingly low and perhaps a reflection of patients' desire to avoid overburdening the healthcare system during the pandemic.

While **11%** of respondents had been accessing mental health support prior to the pandemic, our data indicates that approximately **30%** of shielders may seek mental health support in the future. This is deeply concerning considering the reports of individuals losing access to support during the pandemic.

## Our recommendations

- Work should be undertaken to **identify the reasons some individuals lost access to mental health support** during the pandemic. This **support must resume as a matter of priority**.
- We expect the rise in demand for mental health support to continue. **The NHS and UK Government must be ready to meet this increased demand and proactive support should be introduced**, particularly for the clinically extremely vulnerable / shielding populations.
- At particular risk of COVID-19, additional research should be performed to **assess the mental health impact of COVID-19 on the blood cancer community**.

“The pandemic has made me think about my diagnosis numerous times a day which I had stopped doing previously. It makes me tearful and all the initial feelings of worry and fear I had when getting my diagnosis have engulfed me again.”

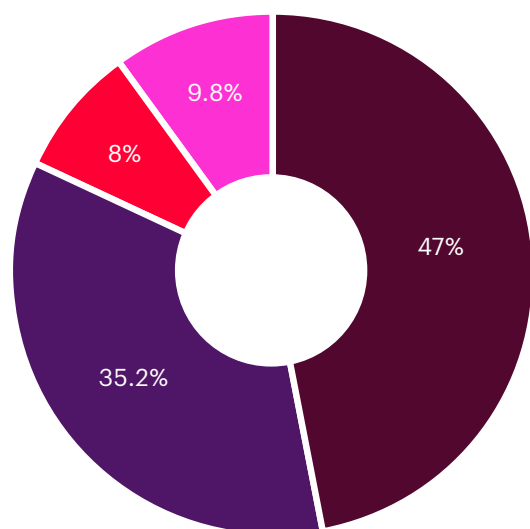


# Impact on... Treatment and care

When COVID-19 spread across the country the NHS rightly reconfigured its services to deal with the pandemic. These measures involved the building of the NHS Nightingale Hospitals; the reallocation of NHS staff; splitting hospitals into 'green' and 'red' zones; and changes to NICE guidance to allow for greater flexibility in cancer management. While these efforts prevented the NHS becoming overwhelmed as first feared, unsurprisingly these changes affected the treatment and care of patients.

**47%** of respondents reported that their blood cancer appointments and treatment had been impacted in some manner by the pandemic. We have reason to believe that the true percentage is actually higher: many respondents told us that their next appointment had not been scheduled and as such, hadn't been affected yet.

## Has coronavirus impacted your blood cancer appointments or treatments?

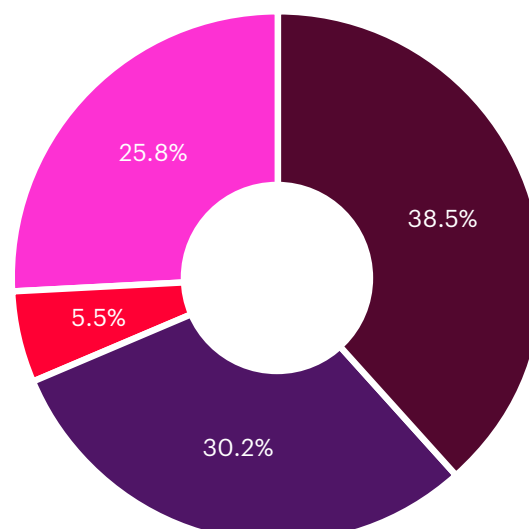


- Yes
- No
- I don't know
- Other

While some respondents reported having their appointments cancelled or delayed, many others had their face-to-face consultations swapped to a telephone conversation. A number of respondents also reported having their treatment altered such as their blood tests postponed, while others informed us of a pause or early termination to their chemotherapy.

Our survey told us that while **52%** of those with scheduled care had been attending their appointments during the COVID-19 pandemic, **45%** had not due to disruptions outside of their control e.g. due to appointment cancellations or postponement. Worrying, **7%** of those with scheduled care had not been attending their appointments out of choice, typically due to concerns over visiting a hospital in the midst of a pandemic.

## Have you been attending your blood cancer appointments and treatment?



- Yes
- No, but this has not been my decision (e.g. my appointments have been cancelled)
- No, but this has been my decision (e.g. I am worried about visiting a hospital during the pandemic)
- No, I don't have any appointments or treatment at present

When these individuals were asked what would give them the confidence to attend their appointments again, respondents said they would be comforted by more information about the safety measures in place (27%) or by more reassurance from their treating team (13%). Strikingly, 47% said nothing would give them the confidence to visit a hospital during the current pandemic. This figure points to the extreme anxiety of many in the blood cancer community; the efficacy of the Government's messaging in instructing people to 'Stay Home. Protect the NHS. Save Lives'; and the difficulty we are likely to face in reassuring patients that hospitals are both open and safe.

“ I have cancelled my appointment. I haven't been for blood tests etc. as I don't want to be in a hospital at the present time. ”

## Our recommendations

- The Government's message in March 2020 of 'Stay at Home. Protect the NHS. Save Lives' was effective. This message however resulted in some putting their health needs secondary to that of the health service, and to avoid seeking help even when necessary. As cases begin to rise again, we are pleased to see that the UK Government are making efforts to **encourage people to visit their healthcare professionals** (e.g. NHS England's Help Us Help You campaign).
- Accordingly, **the NHS and hospitals must take appropriate measures to protect vulnerable patients from COVID-19** and to communicate their efforts clearly to create confidence. Regular testing of NHS staff, even those with no symptoms, will be important in this regard.
- Work to **understand the impact of COVID-19 on blood cancer treatment and care** (e.g. changes to chemotherapy and stem cell transplantation) must continue and acted upon to **restore disrupted services**.
- We have seen **rapid change and innovation across the healthcare system** such as the adoption of online consultations, greater flexibility in the management of cancer, and additional treatment options. The **efficacy of these measures should be reviewed and retained if beneficial**.

# Impact on... Work and finances

COVID-19 meant many businesses couldn't operate in the normal way. Some cut costs by letting their employees go or by furloughing members of their workforce. While some employees in key areas continued going to work, this was not possible for many, particularly those who were shielding.

**42%** of shielding respondents were in work at the time of completing our survey (**37%** were an employee, **6%** were self-employed). While **41%** of our in-work shielding respondents were able to continue working from home, **16%** were furloughed as a result of the pandemic, and a further **13%** couldn't work from home but were eligible for sick pay having received a shielding letter.

Regrettably, despite the furlough scheme and Government support for shielders, we heard from a small number of individual who were forced to stop shielding because they couldn't work from home (six people); were forced to find alternative work to continue shielding (one person); or lost their job as a result of the pandemic (six people). Furthermore, 54 self-employed individuals reported that they were unfortunately unable to continue their business during the pandemic.

While most employers were supportive of their employee's need to shield (**79%**), **17%** of respondents said their employer had only been partially supportive, and **5%** told us their employer had been entirely unsupportive.

Unfortunately, **17%** of survey respondents reported that they had been financially impacted by the COVID-19 pandemic. Similarly, **34%** of respondents reported having received some form of financial support. The nature of this support varied greatly – from the Government Job Retention Scheme, business grants, and Universal Credit, to financial support from friends and family members.

This impact on the jobs and finances of individuals with blood cancer will clearly lead to fear and uncertainty, and in turn, have a detrimental effect on some people's mental health. With shielding now ended and many with blood cancer forced to choose between going back to work and risking their health, we recently called on the Chancellor to **#SaveOurShielders** (see 'Our recommendations').

**“ It feels like it has driven a wedge between myself and my employer – I feel they have not been supportive whilst I have taken a very cautious approach due to my poor immune system following treatment. ”**



# Impact on...Carers

Many people with blood cancer are thankfully surrounded by supportive loved ones. These carers provide invaluable support but are all too often overlooked. We know from our previous work that carers are also affected by the impact of blood cancer and often experience their own unique practical and emotional challenges.

Over one thousand people (i.e. **19%**) that responded to our survey identified themselves as a carer. These respondents fell into a range of categories but were predominantly partners (**48%**), parents (**25%**), and other family members (**15%**) of an individual with blood cancer.

## Mental health

We were interested in capturing the unique mental health challenges faced by these carers during the COVID-19 pandemic. For those living in a different household, carers told us how difficult it was not seeing their loved one. For those residing in the same household, many carers told us how challenging it was living together but physically separated, and about their fears of infecting their vulnerable loved one with the virus.

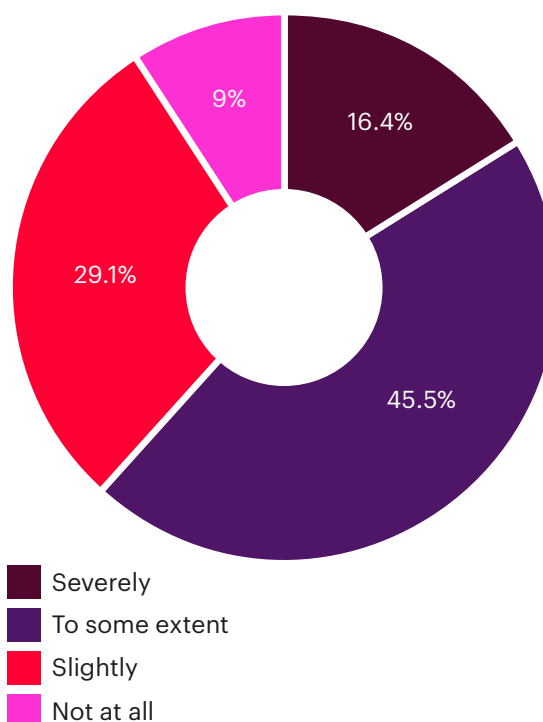
**91%** of carers felt their mental health had been affected by the COVID-19 pandemic. Strikingly, **16%** of these carers described this impact as 'severe' – six percentage points higher than people with blood cancer. Further to this, **73%** of carers told us that supporting their loved one with blood cancer through the pandemic had caused them additional stress.

**“My husband is still too frightened to go out and we haven't had anyone in the house since the start. I am also shielding as I am afraid I will bring it in to him.”**

## Views on shielding

**72%** of carers told us they were living in the same household as someone with blood cancer through the pandemic. **87%** of these respondents considered themselves to be shielding with their vulnerable loved one. These carers told us that this had impacted their lives in a number of ways, such as negatively affecting their mental health and wellbeing, their work (**27%**), their finances (**22%**), and their relationship with the person affected by blood cancer (**13%**).

## To what extent has coronavirus affected your overall mental health / wellbeing?

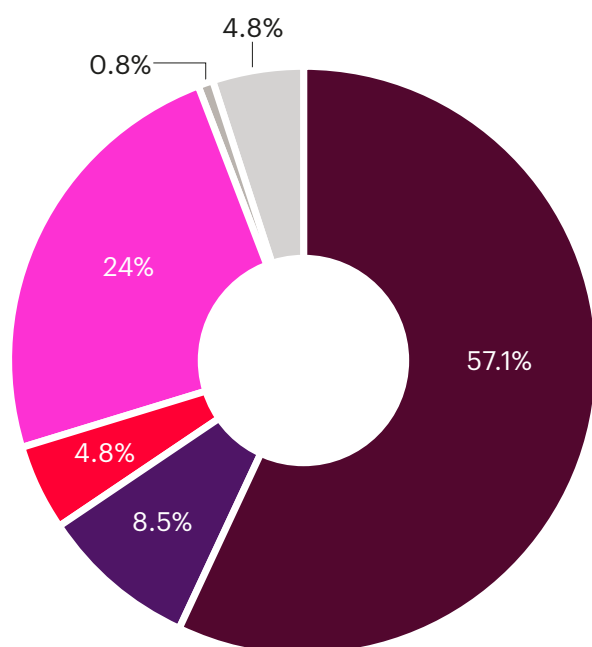


# Attitudes towards shielding

## Shielding letters

In March 2020, the four UK Governments introduced 'shielding' – a series of measures to protect those at very high risk of severe illness from COVID-19 by minimising their interactions with other people. Over two million people in the UK were advised to shield – a group including ~200,000 people with blood cancer. Shielding not only protected vulnerable people but made them eligible for shielding support from the Government such as food and medicine deliveries, and financial benefits.

### Have you received a letter asking you to shield?



- Yes, and I was expecting it
- Yes, but I didn't expect one
- No, and I didn't expect one
- No, but I thought I'd get one
- I don't know
- Other

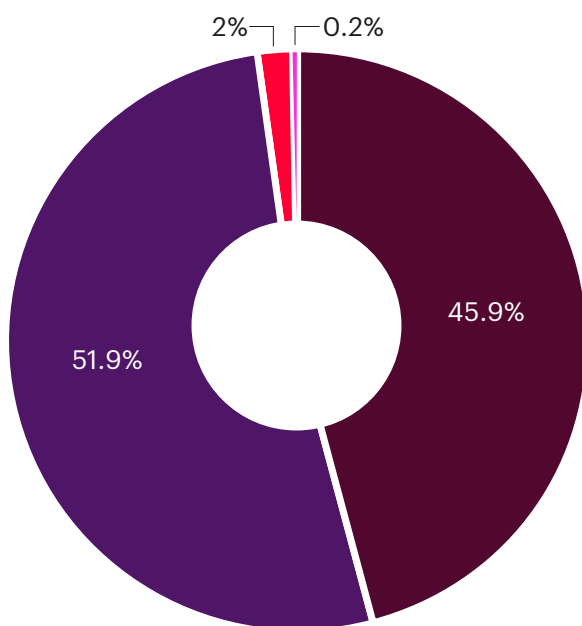
Those identified as being at high risk from COVID-19 were advised to shield by the NHS. We asked survey respondents with blood cancer if they had received such a letter or text instructing them to take this action. Across the duration of the survey **57%** of respondents told us yes and that they had been expecting such a notification, and **9%** said yes but that they hadn't expected one. Conversely, **24%** of respondents told us that they had not received a letter despite expecting one.

Our data indicates that this situation slowly improved over time: in early March, **38%** of respondents had received a letter vs. **58%** who had not, compared with June in which **82%** of respondents had received a letter vs. **13%** who had not. However, these figures remain a cause for concern, indicating that potentially thousands of highly vulnerable people did not receive instructions to shield as the pandemic spread across the country, and that many were still waiting to receive advice after the shielding programme formally ended.

## Shielding

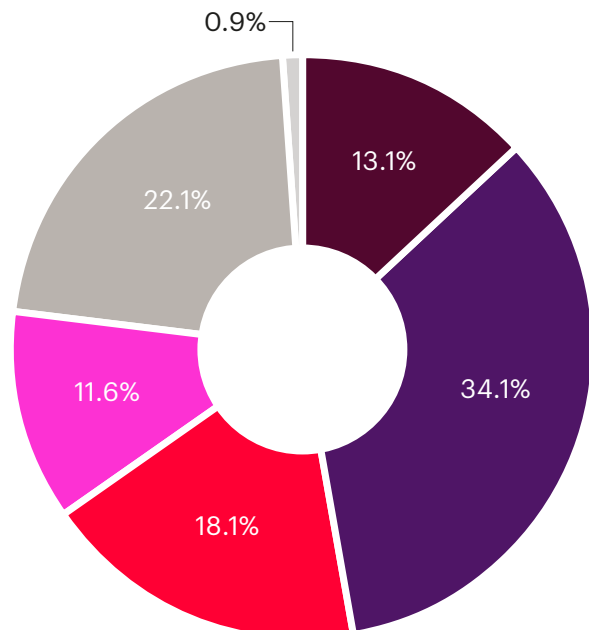
Despite persistent issues with the NHS shielding letters, our survey told us that members of the blood cancer community were diligently shielding, with **46%** of respondents following guidance 'very strictly' (e.g. not leaving the house at all) and **52%** following the guidance 'quite strictly' (e.g. leave the house as little as possible) i.e. **98%** adherence. Answers to our open text questions on the topic indicated that people deviating from the shielding guidance were primarily doing so for unavoidable reasons or to cautiously exercise far away from other people.

## How strictly have you, or people in your household been following shielding guidance?



- Very strictly (e.g. I've / they've not left the house; I / they keep a strict distance from others in the house)
- Quite strictly (e.g. I / they go out as little as possible, careful to avoid other people; inside the house I / they make some effort to avoid others)
- Not very strictly (e.g. I / they go out regularly to busy places like supermarkets; I / they don't avoid others in the household)
- Not at all (e.g. I / they don't follow any of the guidance)

## What's the maximum length of time you could stand to continue shielding?



- Less than one month
- 1-3 months
- 4-6 months
- 7-12 months
- Indefinitely
- Not applicable

We also asked shielders how long they could stand to continue shielding for. While **47%** said they could shield for up to an additional six months, **30%** said they could stand to shield for another six to 12 months. Considering the level of shielding adherence and concern over the easing of the lockdown, it is perhaps unsurprising that **22%** of respondents said they would be willing to shield indefinitely to protect their health.

## Easing of the lockdown

In July 2020, the UK Governments announced an easing of the lockdown. We found that **65%** of respondents understood the guidance compared

with **31%** who partially understood it and **4%** who did not. Changes to lockdown guidance was met with concern, with **74%** of respondents worried about the easing of measures. When we asked shielders what steps they were likely to take as the lockdown eased, respondents were more likely than not to stop their children returning to school; less likely to discourage other household members from returning to work; more likely to ask friends and family members not to visit their household; less likely to socially distance from members of their own household; and more likely to not go out to work even if permitted.

## Our recommendations

- Any **changes to shielding must be communicated clearly and in advance** of implementation. As a trusted voice, **charities and patient organisations should be involved** in any messaging to ensure future guidance is clear, aligned, and available when changes are made public.
  - Considering the threat of COVID-19 and initial lack of clinical data on the virus, it was right that blanket shielding guidance was first issued. As we move forward and better-understand the virus however, **a more nuanced approach should be taken** (e.g. accounting for disease type and stage of treatment).
  - If shielding is reintroduced, **the shielding patients list must be kept up to date and continually reassessed** as clinical data is published. **Notifications to shield must go out in a timelier and more coordinated manner.**
  - The **QCOVID risk prediction tool should be made available to the public** for individuals to better-understand their personal risk and facilitate conversations with their clinical teams.
  - To ensure consistency, efforts must be taken to improve coordination between the devolved administrations, Government departments, and central / local Government.
- Shielding support ended in July leaving many people with blood cancer faced with the choice of protecting their health or keeping their jobs. In our **#SaveOurShielders** campaign, we called on the Government to:
    - Re-open the furlough scheme to those advised to continue shielding or where their employer could not create a COVID-free workplace.
    - Ensure those diagnosed with blood cancer were promptly added to the list of shielders.
    - Commit to the re-introduction of a full support package to those asked to shield again if the infection rate were to rise significantly.
    - Accordingly, we were pleased with the Government’s decision in November to extend the furlough scheme until March 2021.

**“I cannot imagine coping with my current levels of anxiety and unhappiness longer than one year, but I would shield indefinitely if the situation did not improve to a much greater level of safety.”**

# Our response to your responses

The responses to our survey told us the questions, concerns, and needs of the blood cancer community regarding COVID-19. Collectively, these responses have helped us rapidly produce new information on the pandemic and provide additional support to those affected through our support services and online communities.

We also used our survey to make sure people affected by blood cancer are visible and represented through this challenging time. Using your responses, we have:

- Briefed clinicians, academics, senior members of the NHS, parliamentarians, and the Government on the impact of COVID-19 on the blood cancer community.

- Established a call-back service to ensure those badly affected by COVID-19 receive additional support.
- Raised the profile of blood cancer in the regional and national press.
- Helped NICE produce rapid clinical guidance on cancer treatment during the pandemic.
- Provided evidence to parliamentary select committee inquiries.

As the situation with COVID-19 evolves, Blood Cancer UK will continue to inform, support, and advocate for the blood cancer community. To the ~6,500 people who completed our survey – thank you.



# Acknowledgements

Dr Ross P. Coron (Policy, Campaigns, & Engagement Team) performed our COVID-19 survey, analysed the results, and produced this report. Many thanks to the other teams at Blood Cancer UK who provided input to this work and to the survey respondents for their participation. If you have any questions, comments, or feedback on this work, please get in touch via [policy@bloodcancer.org.uk](mailto:policy@bloodcancer.org.uk).



Blood Cancer UK is a trading name of Bloodwise. A company limited by guarantee 738089 (registered in England and Wales). Registered charity 216032 (England and Wales) SCO37529 (Scotland) © 2021 20121/0121