

# **Impact of Covid-19 on people with rare and less common cancers in England**

## **Results of 2020 patient survey**

July 2020

# About the survey

- Cancer52 ran an online survey of people with rare and less common cancers during June 2020. Respondents were recruited via member charities' networks and communications. Since respondents were found via Cancer52's member charities, respondents to the survey are more likely to be using the support of charities and more likely to have been diagnosed some time before the pandemic began.
- 1,410 people responded from across the UK. 1052 of these people were from England. The data that follows is England specific.
- The survey consisted of 26 questions. A list of these can be found in the appendix.
- The survey asked participants about the impact of the Covid-19 pandemic (the period beginning mid-March 2020 until the end of June 2020), their cancer treatment and care during this time, whether they had been shielding and the impact of shielding, and what should be done differently in the future.

# Key points: One

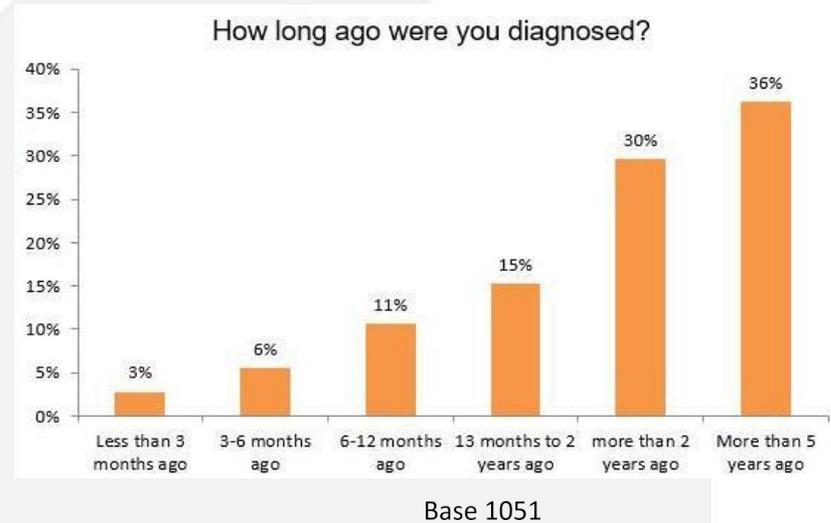
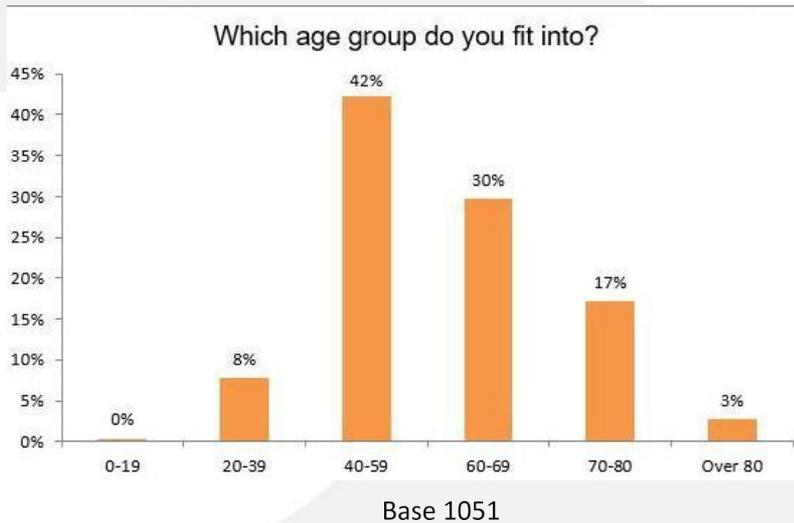
- People with rare and less common cancer are as concerned about Covid-19 as they are about their cancer. The majority believe their risk from Covid-19 is medium or high.
- People turned to patient groups and online forums most often for sources of information as well as their cancer team, the NHS and Government websites, and charity websites and helplines.
- Of those who tried to contact their cancer team during the pandemic, 9 in 10 were successful.
- Some people recently diagnosed (within the last three months) had had treatments delayed.
- There has been some disruption to treatments and follow up appointments and many appointments have moved to telephone or video.

# Key points: Two

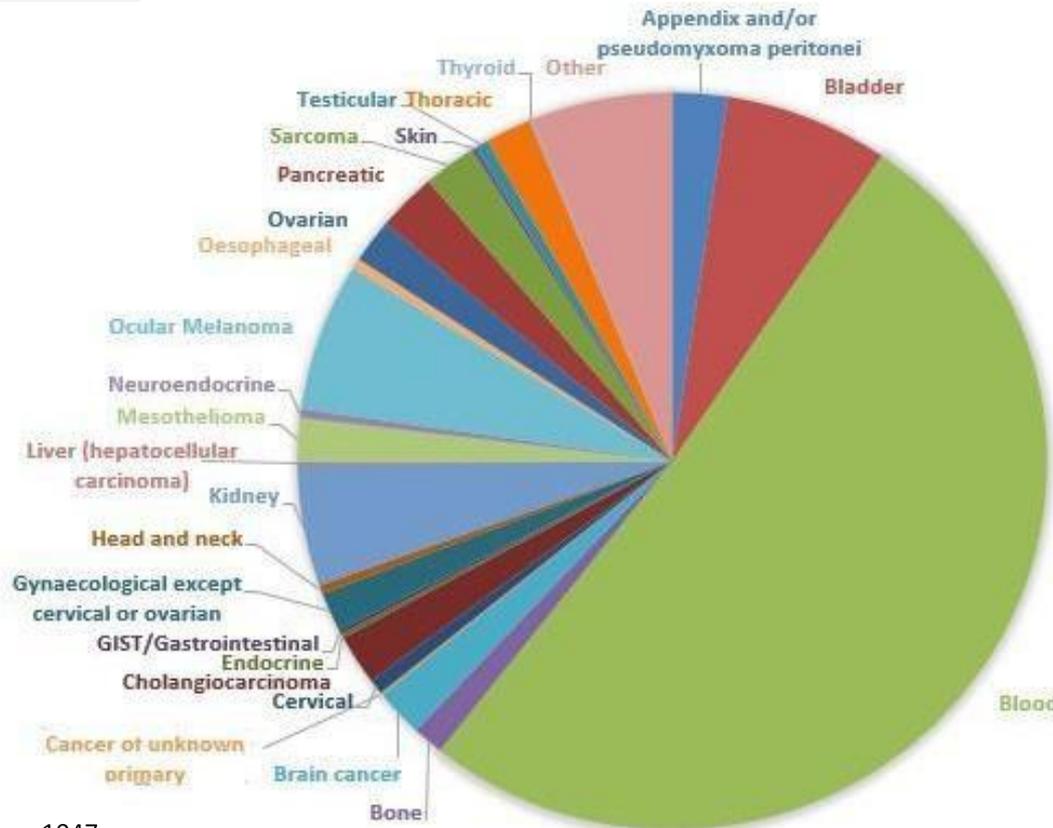
- 70% of people with rare and less common cancers are shielding. Those shielding have found the mental impact of shielding difficult, as well as facing difficulties obtaining food or medicines. They thought that communications about shielding could have been better. People are concerned about shielding ending.
- There are positive changes people would like to retain, such as phone or video appointments and treatments delivered in or to the home.
- Negative aspects included not being able to be seen face to face, not being able to have visitors at hospital, and delays to tests, treatment and follow up appointments.

# About the respondents

- 1052 people in England responded to the survey
- They had a range of rare and less common cancers
- About one third had been diagnosed less than two years ago, one third between two and five years ago, and one third more than five years ago



# Type of cancer



Half of respondents to the survey had blood cancer. An analysis comparing answers from those with blood cancers to those with all other cancers was undertaken and the results are in the appendix to this survey.

# Cancer type - number of respondents

Appendix and/or pseudomyxoma peritonei	25	Kidney	56
Bladder	74	Liver (hepatocellular carcinoma)	1
Blood	536	Mesothelioma	20
Bone	14	Neuroendocrine	4
Brain cancer	22	Ocular Melanoma	68
CNS	0	Oesophageal	5
Cancer of unknown primary	1	Ovarian	20
Cervical	7	Pancreatic	27
Childhood and young people	0	Penile	0
Cholangiocarcinoma	23	Sarcoma	24
Endocrine	2	Skin	2
GIST/Gastrointestinal	2	Stomach	0
Gallbladder	0	Testicular	6
Germ cell	0	Thoracic	21
Gynaecological except cervical or ovarian	18	Thyroid	1
Head and neck	4	Other	64
		<b>Total</b>	<b>1047</b>
		<b>Skipped</b>	<b>5</b>

# Concerns about Covid-19

## Risks of Covid-19

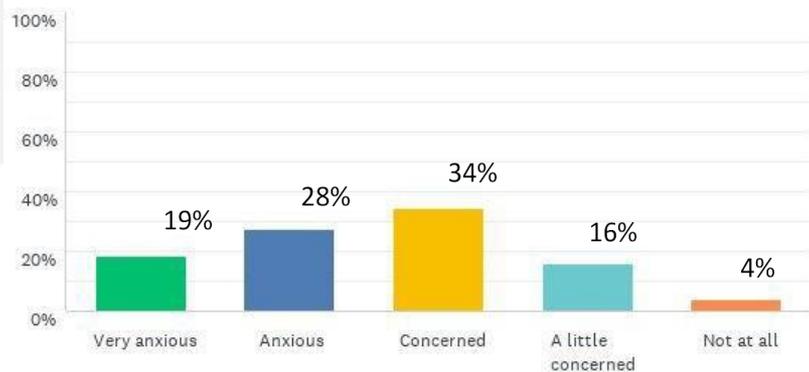
- 18 (2%) people who responded to the survey had had Covid-19
- Of those who had not had Covid-19:
  - One third felt their risk of Covid-19 was high
  - Another third felt their risk was medium.

## Attending Hospital

- 70% of all respondents were still happy to attend appointments even if it meant they had to go to a hospital or another medical centre.
- 8% were not happy
- 20% were unsure.

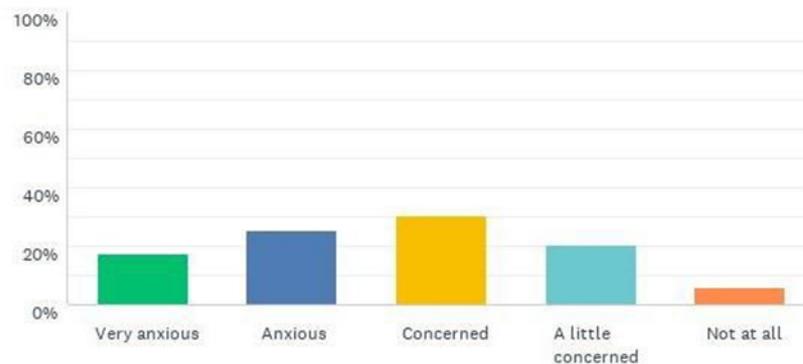
# People are as worried about Covid-19 as they are their cancer

Q9 How anxious do you feel about Covid-19?



Base 1033

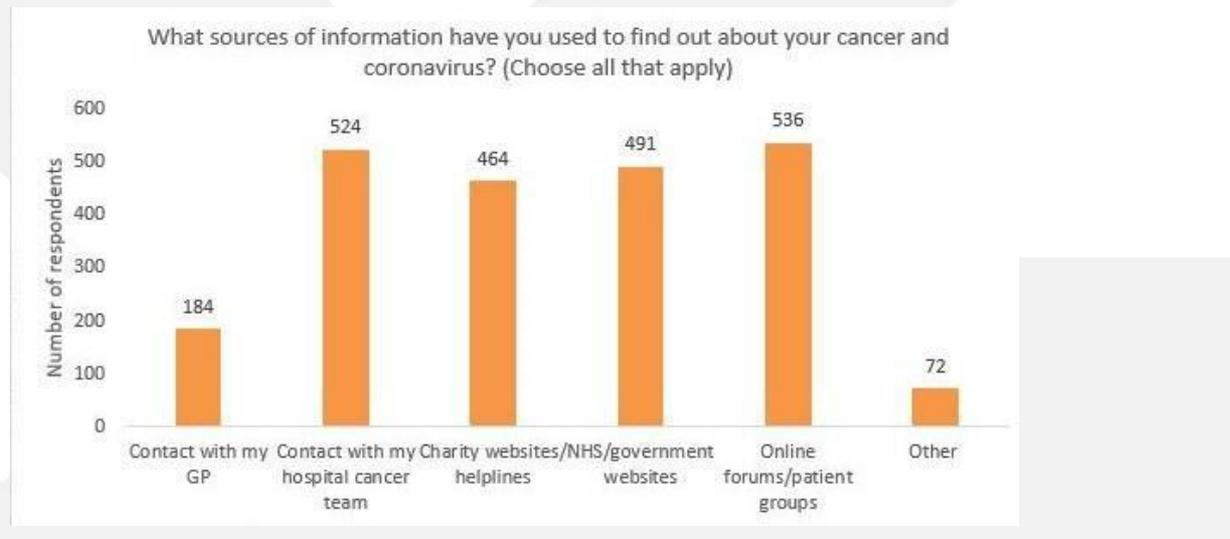
Q10 How anxious do you feel about your cancer?



Base 1033

# Sources of information during the pandemic

People turned to patient groups and online forums most often for sources of information as well as their hospital cancer team, the NHS and Government websites, and charity websites and helplines.

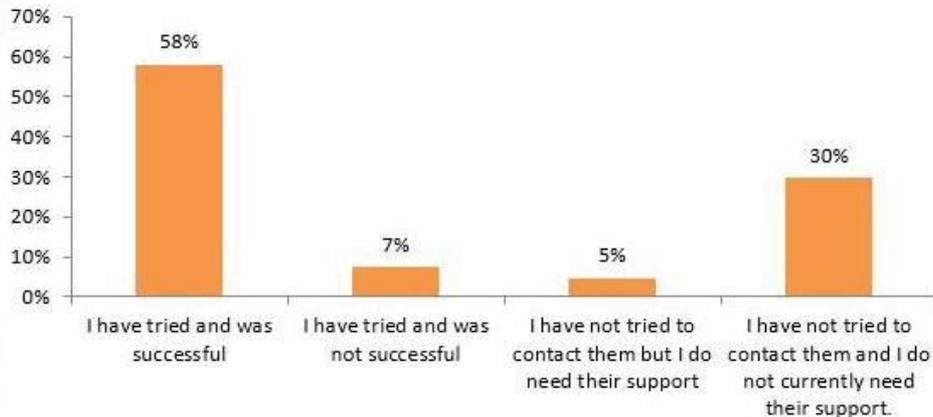


Base 980

# Support from cancer teams

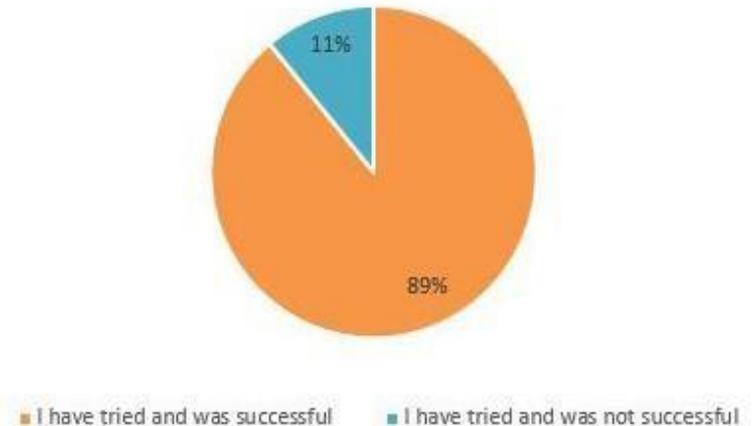
Of the 640 people who tried to contact their hospital cancer team during the pandemic, 9 in 10 were successful.

If you have tried to contact your cancer team during the pandemic, were you able to get in contact with them?



Base 978

Those who tried to contact their cancer team



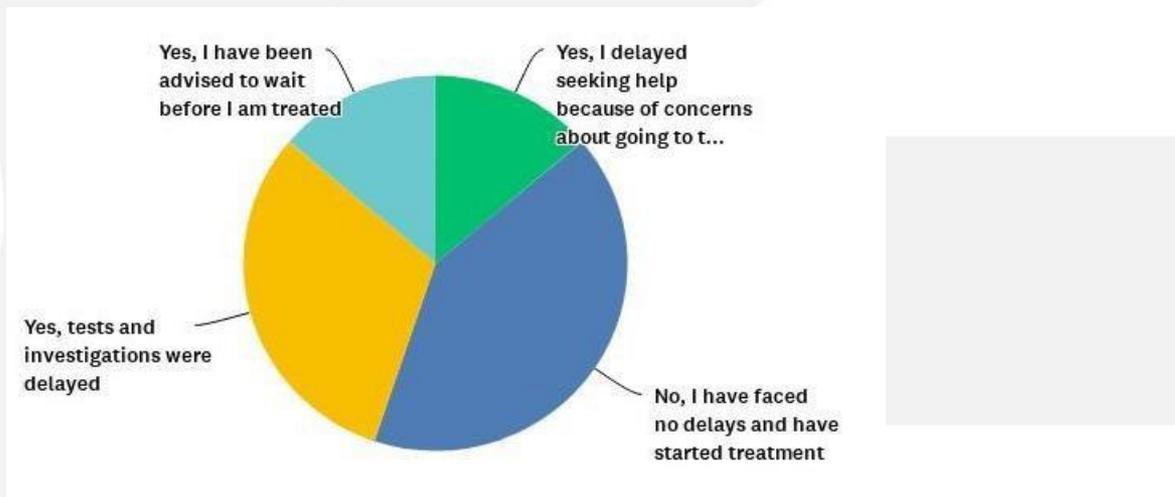
Base 640

# Where were respondents in the pathway?

- Of all respondents, 29 (only 3%) had been diagnosed within the last three months.
- 51% of respondents (534) told us they were receiving, or due to start, treatment.
- 24% of people (156) who responded to the survey were in surveillance or watch and wait.
- 16% of people (239) who responded to the survey were in follow up.
- Of the remaining respondents, some were undergoing palliative or supportive treatment and others were in remission.

# Diagnosis

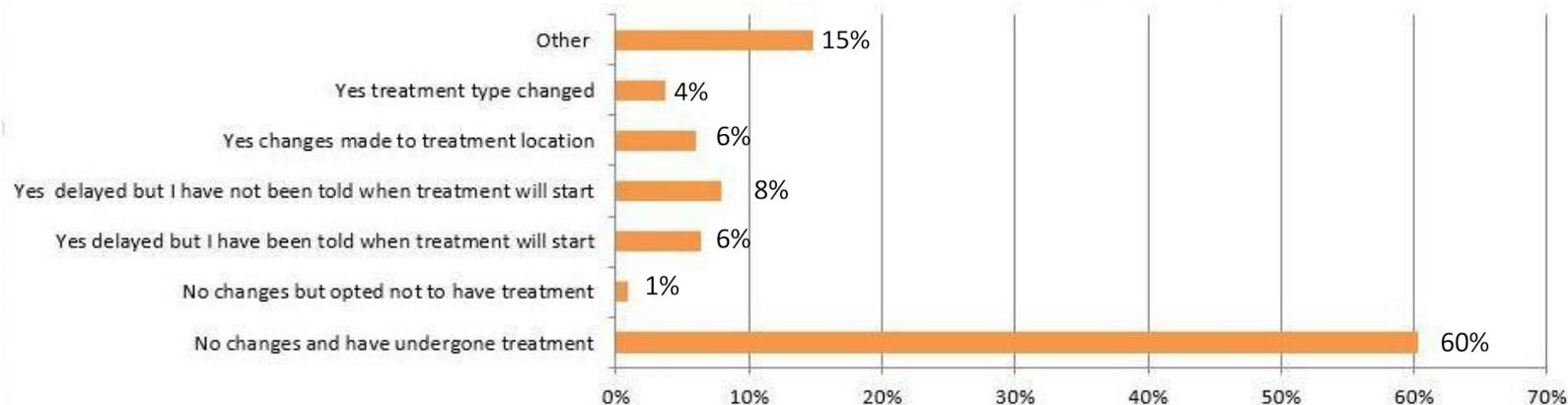
- Of all respondents, 29 (only 3%) had been diagnosed within the last three months (between March and June 2020).
- Of these 29, four delayed seeking help because of concerns about going to the GP during the pandemic.
- Nine had had tests and investigations delayed.
- Four had been advised to wait for treatment.
- The remaining 12 faced no delays and have started treatment.



# Treatment

- 51% of respondents told us they were receiving, or due to start, treatment.
- Of these 534 people, 60% had had no changes to their treatment during the pandemic.

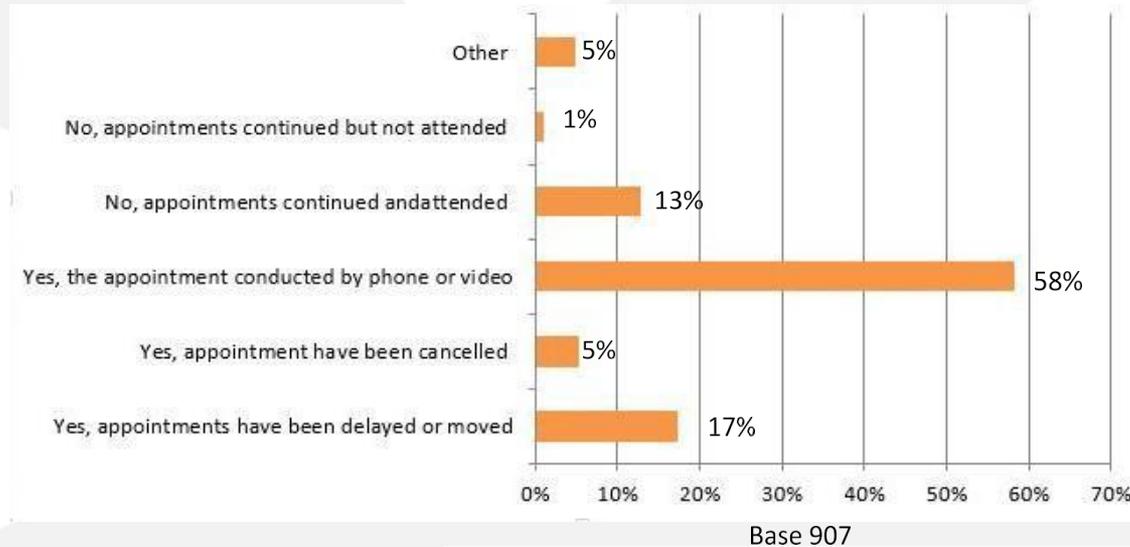
If you are currently being treated, or are due to start treatment (including surgery, radiotherapy, immunotherapy or chemotherapy) in the next 3 months, have you been told of any changes?



Base 534

# Changes to outpatient appointments

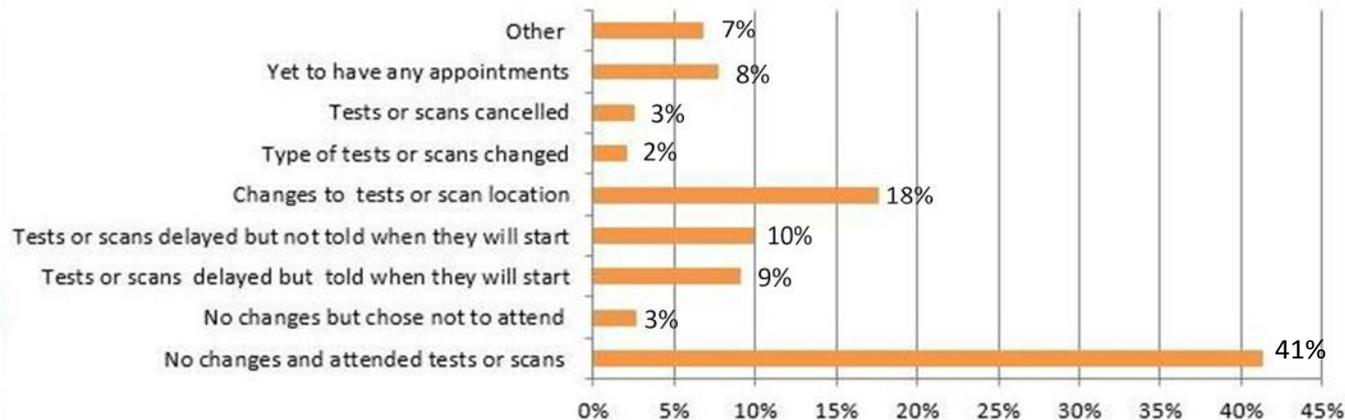
- 60% of the 907 respondents who attend follow up outpatient appointments had seen these conducted by phone or video.
- A quarter (206) have had their appointments moved, cancelled or delayed.



# Changes to tests and scans

Over 40% of the 894 people who receive regular surveillance had no changes to their tests or scans. About a quarter had tests or scans delayed or cancelled.

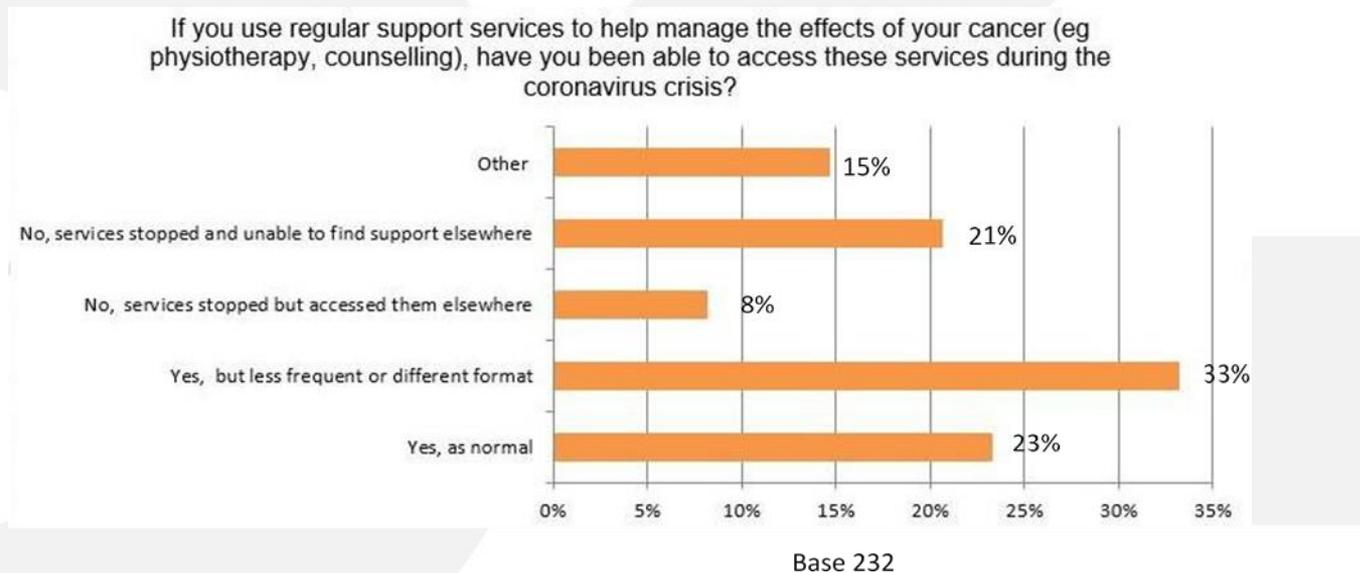
If you receive regular surveillance to monitor your cancer, such as blood tests or scans, have you been told of any changes?



Base 894

# Support services

- About a quarter of all respondents (232 people) use support services such as physiotherapy or counselling regularly.
- For one in five of these people, services have stopped and they have been unable to find help elsewhere. Two out of five of these people have accessed services elsewhere, less frequently or in a different way.



# Clinical trials

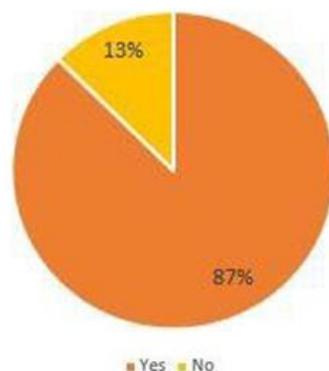
- 67 people were in a trial or were about to start one when the pandemic began.
- For over a third of these people, their clinical trial was paused, ended or they were removed for safety concerns.



# Shielding

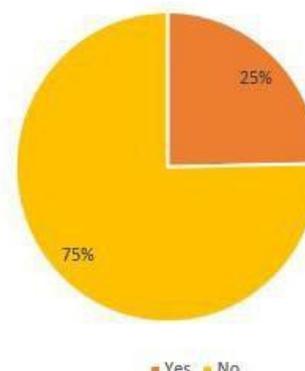
- 70% (686) of people who responded to the survey had been asked to shield
- 69% (667) of people who responded to the survey were shielding.
- 71 people were shielding despite not being asked to do so. This suggests there is a level of anxiety among people not asked to shield.
- 86 people were **not** shielding despite being asked to do so.

If you were told to shield, did you?



Base 686

If you were not told to shield, did you anyway?

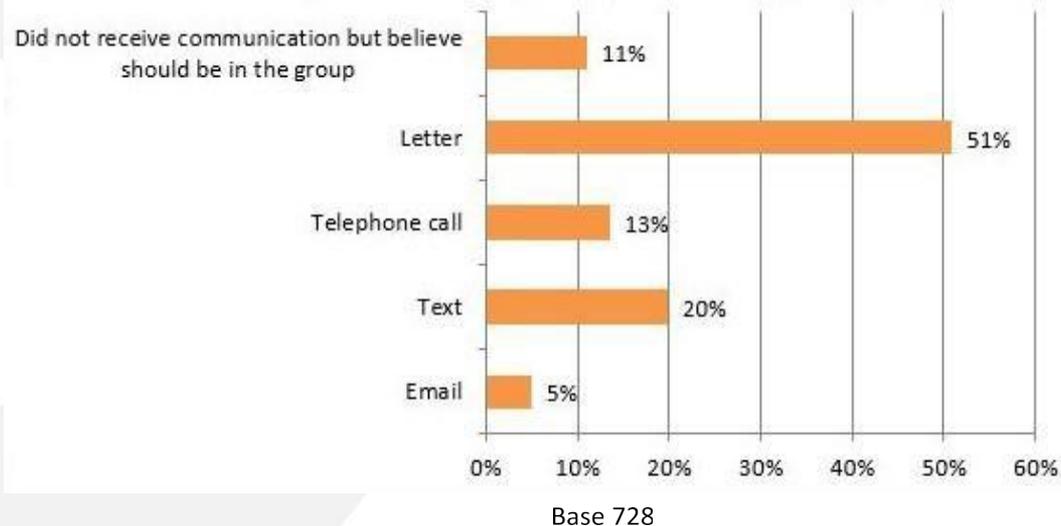


Base 303

# Communications about shielding

- 19% were informed by their GP that they should shield, 30% by their hospital team, 36% by the Government and 15% by other means.
- Over half were told they should shield by letter.

If you were informed you should shield, by which method were you first informed that you are in the extremely vulnerable group (shielding group)?



# Concerns about shielding

Respondents were asked if they had any concerns about shielding.

- Some people had not found shielding a problem.
- Some people felt lucky because their whole household had chosen to shield with them, they had a garden or a helpful partner.
- Others had found it difficult, especially people who lived alone and/ or are single parents. (The survey did not ask about household status).
- Some had taken what they saw as sensible steps and ignored some of the shielding rules.

People's concerns about shielding included:

- Unsure about whether they should be shielding. People mentioned getting their letter late or GPs and hospitals giving conflicting information.
- Government communications being unclear, and often not mentioning people shielding. People said they felt 'forgotten' in the daily briefings.

# Concerns about shielding (cont.)

- Difficulty accessing food and shopping, particularly in the beginning of lockdown.
- Other family members shielding as well, to protect them.
- Missing family and friends.
- Having to rely on others for food and shopping.
- Concerns about conducting caring responsibilities when they could not go out anymore.
- Children not being able to go back to school.
- Work and money issues.
- Not being able to go out to exercise, to help both their mental and physical health.

**Mental impact (boredom, anxiety, depression and loneliness) was a huge issue.**

# Selected quotes - shielding

I don't know how I will feel getting out of shielding, it feels like I am in a bubble and the world is moving too fast around me

The sheer loneliness of not talking to people for weeks

I feel safe at home. Luckily I can work from home. My Employer has been brilliant. I will shield for as long as I need to in order to feel safe.

I know it's for my own good

My cancer was diagnosed at the time of lockdown. It was the worst possible timing. I was unable to get physical check ups on lung surgery that I had a couple of weeks before lockdown, even though my wound was sore and painful. I have also been unable to have any physical appointments and follow-on CT scans were delayed. Apart from my wife who has self-isolated with me I have had no other physical contact. It has been very hard coping with this after such an awful diagnosis at the time of lockdown and it has been difficult to get some of the things that we have needed and it has often been a struggle.

# Worries about shielding ending

People expressed concerns about shielding ending.

- Many of them said they felt 'safe' shielding and accepted it was necessary. However they also said it had gone on a long time.
- Some wanted more guidance about the risks so they could make up their own minds about risks to take.
- People expressed concerned about others not complying with social distancing.
- Some were worried about going back to work safely.

# Positive impact on treatment or care

Respondents were asked if there had been a positive impact on their treatment or care due to the Covid-19 pandemic.

- Many highlighted better communication, often by phone or video, saving people time, the need to travel and the risk of infection that attending hospital would present.
- Some liked the benefits of having their treatment at home or medication delivered to the home rather than the need to collect them from hospital.
- Some mentioned treatment or appointments being speedier.
- A few mentioned the benefits of private treatment or having quieter wards with fewer visitors.
- Many respondents reported no positive impact.

# Selected quotes - positive impact

I like that some appointments are phone or video. Before COVID I could be at the hospital several times in a week for different departments. I also like email as a way of communicating

No visitors allowed to the wards!  
Brilliant! So quiet and calm.

The biggest positive would be that any scans or tests I've needed, I have been able to book and attend within days, rather than weeks.

Telephone consultations with my GP and delivery of my medication by the pharmacy attached to my GP practice, again less prolonged contact with sick people in GP surgery & pharmacist's.

The telephone consultations with my consultant have been a great improvement on sitting around for at least an hour in a narrow and depressing hospital corridor full of germs

# Negative impact on treatment or care

Respondents were asked if there had been any negative impacts on their treatment and care.

- Many highlighted the lack of communications and updates from their GP or cancer team.
- Some had experienced increased anxieties and impact on their mental health.
- Many mentioned delays or changes to treatment, scans and follow up appointments.
- Some missed not being able to see staff face to face or being examined in person by a clinician.
- A few found it difficult not being able to have visitors in hospital or with them at appointments.
- Some respondents reported no negative impact.

# Selected quotes - negative impacts

That it does not feel safe to attend a medical setting. After cancelling 2 scans I braved attending a third appointment only to see 4 members of staff huddled talking with no face masks on. That I couldn't get chemo in a 'clean' site with ring-fenced staff, so it felt like dicing with death to go in for treatment.

Was also hard having conversation around end of life whilst on my own in hospital.

Phone consultations instead of face to face however I understand this is a necessary precaution.

Op cancelled and feel abandoned.

No sign of a follow up appointment despite Government saying services have returned to normal. The stress and worry that cancer has returned is hard to live with. I'd rather have the option of being able to decide if I want to go in for check up and risk catching than COVID than being told no check up. There's a greater chance of cancer killing me than COVID 19 cancer patients have been left to flounder while the elderly have been protected. More people die of cancer each year than they do of COVID.

# What could be done to make it easier next time?

Respondents were asked: 'Do you have any ideas on what could have been introduced to make this time easier for you?'

Common suggestions included:

- Much better communications from Government, particularly in relation to people who are shielding.
- Carrying on cancer services as normal or providing Covid free centres.
- Contact from medical team and updates on treatment and care, via phone or video contact if required.
- Provision of mental health support services, including counselling.

# Selected quotes - what should be done next time?

I am very focussed on keeping myself safe and I know help us out there had I needed it. My husband thankfully does all the shopping and collects my prescription! Free chocolates would help!

Video calls with my CNS maybe once a week would have made me feel so more supported.

Making sure cancer treatments were not sacrificed.

Communication! A letter to patients explaining the personal impact on them rather than leaving us in the dark.

It would have been good to have had some online sessions on positive thinking.

Dedicated times for shielding people to have outdoor exercise.

# Next steps

## We will

- share these findings with key stakeholders to help inform work to rebuild and recover services, and to prepare for any future waves of the virus.
- develop key recommendations for the Government, NHS England, Cancer Alliances and NHS services based on these findings, and the knowledge and experience of our member charities.
- continue to share intelligence among our member charities, and monitor the situation for, and recovery of services for, people with rare and less common cancers.

# Appendices

# Appendix One: Blood cancer vs all other cancers

Approximately half of the respondents to this survey had a blood cancer. There were some differences in answers between those with blood cancers and those with all other types of rare and less common cancers.

- Those with blood cancers were more likely to believe their risk of Covid was high compared to those with all other cancers (36% vs 26%)
- Those with blood cancer were less likely to be very anxious about their cancer than those with all other cancers (10% vs 26%)
- Those with blood cancer were less likely to be happy to attend hospital than those with all other cancers ( 60% vs 82%)
- A greater percentage of those with blood cancers had been asked to shield compared to all other cancers (76% vs 56%).

# Appendix Two: Survey questions

1. What age group do you fit into?

- 0-19
- 20-39
- 40-59
- 60-69
- 70-80
- Over 80

2. What type of primary cancer do you have?

Appendix and/or pseudomyxoma peritonei; Bladder; Blood; Bone; Brain cancer; Cancer of unknown primary; Cervical; Cholangiocarcinoma; Endocrine; GIST/Gastrointestinal; Gynaecological except cervical or ovarian; Head and neck; Kidney; Liver (hepatocellular carcinoma); Mesothelioma; Neuroendocrine; Ocular Melanoma; Oesophageal; Ovarian; Pancreatic; Sarcoma; Skin; Testicular; Thoracic; Thyroid; Other

# Survey questions

## 3. Where do you live?

- England
- Wales
- Northern Ireland
- Scotland
- Other

## 4. How long ago were you diagnosed?

- Less than 3 months ago
- 3-6 months ago
- 6-12 months ago
- 13 months to 2 years ago
- More than 2 years ago
- More than 5 years ago

## 5. If you were diagnosed in the last three months, has the coronavirus affected what has happened so far?

- Yes, I delayed seeking help because of concerns about going to the GP during the coronavirus pandemic
- No, I have faced no delays and have started treatment
- Yes, tests and investigations were delayed
- Yes, I have been advised to wait before I am treated.

# Survey questions

6. Have you already had Covid-19, diagnosed by a doctor or positive test?

- Yes
- No

7. If not, what do you feel is your risk of Covid?

- High
- Medium
- Low
- Don't know
- Not applicable.

8. How anxious do you feel about Covid-19?

- Very anxious
- Anxious
- Concerned
- A little concerned
- Not at all.

# Survey questions

9. How anxious do you feel about your cancer?

- Very anxious
- Anxious
- Concerned
- A little concerned
- Not at all.

10. Are you currently having treatment or due to have treatment?

- Yes
- No
- In follow up
- No - in surveillance - watch and wait
- Not applicable
- Other

# Survey questions

11. If you are currently being treated, or are due to start treatment (including surgery, radiotherapy, immunotherapy or chemotherapy) in the next 3 months, have you been told of any changes?

- No, I have not been told of any changes and have undergone treatment
- No, I have not been told of any changes and have undergone treatment but have opted not to have treatment due to concerns about Covid-19
- Yes my treatment of surgery has been delayed but I have been told when treatment will start
- Yes my treatment of surgery has been delayed but I have not been told when treatment will start
- Yes, changes have been made to where I will receive treatment (eg home rather than hospital)
- Yes my treatment has been changed (eg different drug or type of drug or surgery changed to a treatment)
- Other (please specify)

12. Have you seen any changes to your follow up outpatients appointments since the outbreak?

- Yes, appointments have been delayed or moved
- Yes, appointment have been cancelled with no alternative offered
- Yes, the appointment was conducted by phone or video
- No, my appointments have continued as usual and I have attended these
- No, my appointments have continued as usual but I have chosen not to attend due to concerns about Covid-19
- Other (please specify)

# Survey questions

13. If you receive regular surveillance to monitor your cancer, such as blood tests or scans, have you been told of any changes?

- Yes, appointments have been delayed or moved
- Yes, appointment have been cancelled with no alternative offered
- Yes, the appointment was conducted by phone or video
- No, my appointments have continued as usual and I have attended these
- No, my appointments have continued as usual but I have chosen not to attend due to concerns about Covid-19
- Other (please specify)

14. Are you still happy to attend appointments if it means you have to go to a hospital or other medical centre?

- Yes
- No
- Maybe
- Appointments all paused.

# Survey questions

15. What sources of information have you used to find out about your cancer and coronavirus? Choose all that apply

- Contact with my GP
- Contact with my hospital cancer team
- Charity websites/ helplines
- NHS/government websites
- Online forums/patient groups
- Other (please specify)

16. If you have tried to contact your cancer team during the pandemic, were you able to get in contact with them? got

- I have tried and was successful
- I have tried and was not successful
- I have not tried to contact them but do not need their support
- I have not tried to contact them and do need their support.

# Survey questions

17. If you use regular support services to help manage the effects of your cancer (eg physiotherapy, counselling), have you been able to access these services during the coronavirus crisis?

- Yes, I have been able to access this support as normal
- Yes, I have been able to access support but it is less frequent or in a different format (eg virtually rather than face to face)
- No, these services have stopped for the time being but I have been able to access them elsewhere (eg through a charity)
- No, these services have stopped and I have been unable to find support elsewhere
- Other (please specify)

18. Are you in a clinical trial (study) or were you dependent on commencing a clinical trial, and if so has the trial:

- Continued as planned
- Been altered
- Been paused
- Ended
- I have been removed due to safety concerns.

19. Have you been informed that you are in the extremely vulnerable group, sometimes called the shielding group?

- Yes
- No

# Survey questions

20.If you were informed you should shield, who told you to do this?

- Government
- GP
- Hospital team
- Not applicable
- Other (please specify)

21.If you were informed you should shield, by which method were you first informed that you are in the extremely vulnerable group (shielding group)?

- Email
- Text
- Telephone call
- Letter
- Did not received communication but believe I should be in the group
- Not applicable

22.Are you shielding?

- Yes
- No

# Survey questions

- 23.If yes, please tell us your thoughts about shielding including any difficulties you may be facing.
- 24.What positive changes, if any, has the coronavirus caused to your treatment, trial options and care that you would like the NHS to keep (for example video appointments, home treatment)?
- 25.What negative changes, if any, has the coronavirus crisis caused to your treatment, trial options and care that you would like the NHS to address?
- 26.Do you have any ideas on what could have been introduced to make this time easier for you? We cannot promise suggestions can be implemented but we can escalate them.

# Appendix Three: Thank you

Thank you to the following charities who helped develop the survey questions:

- AMMF – The Cholangiocarcinoma Charity
- Anthony Nolan
- Children’s Cancer and Leukaemia Group (CCLG)
- Fight Bladder Cancer
- GIST Cancer UK
- Independent Cancer Patients' Voice (ICPV)
- Kidney Cancer Support Network
- Kidney Cancer UK
- Leukaemia CARE
- Mesothelioma UK
- Myeloma UK
- Neuroendocrine Cancer UK (NCUK)
- OcuMel UK
- Pancreatic Cancer Action
- Sarcoma UK

**With special thanks to the patients who completed this survey**

Cancer52 is a registered charity in England and Wales (1174569) and a company limited by guarantee in England and Wales (7994413)

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