

Welcome to the Cancer52 survey of people with rare and less common cancers.

The following questions ask you about your experiences during the coronavirus crisis. You can complete this survey yourself or ask someone else to complete it on your behalf. It consists of 27 questions and should take about 30 minutes to complete.

Cancer52 is a charity and an alliance of patient groups and charities that represent those with rare and less common cancers. You can find out more about us at [www.cancer52.org.uk](http://www.cancer52.org.uk).

Cancer52 will use the results of this survey to understand how the Covid-19 crisis has affected people with rare and less common cancers particularly on topics like treatment and support; any issues around shielding, and anxieties, concerns and hopes for the future. We will share a full summary of results with our members and use this information in our discussions with the Government, the NHS and industry to continue to push for the best possible care and treatment for people with rare and less common cancers in all circumstances.

Your answers are anonymous and we will not ask you for your name or contact details, although you can opt to keep in touch with Cancer52 and our work at the end of this survey.

The development of this survey has been supported by a grant from GlaxoSmithKline, GlaxoSmithKline have had no editorial input into the content.

#### **Sharing the data with relevant Cancer52 member charities**

If we receive responses from 20 people or more with the same type of cancer, we will share the data we collect in this survey on that type of cancer only with the relevant Cancer52 member charity so that they can understand how the pandemic is affecting the specific groups of people they help. The data we share will be non-identifiable. We are not collecting names or contact details in this survey. You can view our Cancer52 members [here](#). We will not share the data with any other organisations unless legally required to do so. You can read more about our privacy policy [here](#).

You've been sent the link to this survey either because you have given us permission to do so in earlier dealings with Cancer52, or because the charity you are linked to is a member of Cancer52. If you have any questions about this survey or how it will be used please contact [patientvoice@cancer52.org.uk](mailto:patientvoice@cancer52.org.uk).

#### **Thank you for taking part.**

1. Please confirm that you are happy for us to share your anonymised data with Cancer52 member charities in this way and are happy to proceed with the survey

- Yes, I am happy to proceed
- No, I no longer wish to take part

The survey starts below. Please note you can scroll back up to view and change your answers.

1. Which 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
- CNS
- Cancer of unknown primary
- Cervical
- Childhood and young people
- Cholangiocarcinoma
- Endocrine and neuroendocrine
- GIST/Gastrointestinal
- Gallbladder
- Germ cell
- Gynaecological except cervical or ovarian
- Head and neck
- Kidney
- Liver (hepatocellular carcinoma)
- Mesothelioma
- Ocular Melanoma
- Oesophageal
- Ovarian
- Pancreatic
- Penile
- Sarcoma
- Skin
- Stomach

- Testicular
- Thoracic
- Thyroid
- Other

3. Where do you live?

- England
- Wales
- Scotland
- Northern Ireland
- 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

**We would now like to understand a little more about how you are feeling about the current situation.**

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

- Yes
- No

7. If no, what do you feel is your risk of Covid-19?

- 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

9. How anxious do you feel about your cancer?

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



**We would now like to understand if there have been any changes to your treatment and care since the pandemic began.**

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 (please specify)

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 but have opted not to have treatment due to concerns about Covid-19
- Yes my treatment or surgery has been delayed but I have been told when treatment will start
- Yes my treatment or 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 (e.g. home rather than hospital)
- Yes my treatment has been changed (eg different drug or type of drug or surgery changed to a treatment)
- Not applicable
- 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
- Not applicable
- Other (please specify)

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

- No, I have **not** been told of any changes and have attended my tests or scans as usual
- No, I have **not** been told of any changes but I have chosen not to attend due to concerns about Covid-19
- Yes my tests or scans have been delayed but I have been told when they will start
- Yes my tests or scans have been delayed but I have **not** been told when they will start
- Yes changes have been made to where I will have my tests or scans (e.g. in the community rather than hospital)
- Yes my tests or scans have been changed (eg different of scan or test)
- Yes my tests or scans have been cancelled
- I am in follow up but am yet to have any appointments
- Not applicable
- 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

Please explain your answer if you can

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?

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

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  
 I do **not** regularly use support services  
 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
- Not in a trial

**Now we would like to understand more about shielding.**

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

- Yes
- No

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 receive communication but believe I should be in the group
- Not applicable

22. Are you shielding?

- Yes
- No

23. If yes, please tell us your thoughts about shielding including any difficulties you may be facing.

**Your thoughts on changes to the NHS during the pandemic.**

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.