

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

Summary of results of Cancer52 July 2020 patient survey

Introduction to 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. 1,052 of these people were from England. All responses were anonymised
- The survey consisted of 26 questions that 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
- Given the speed at which the scenario is currently changing some elements of these findings were shared with decision makers and influencers before publication of the full report
- Where numbers of responses permitted findings by cancer type were shared with member charities

Key findings

- 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, nine in ten 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
- 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

Key recommendations

- **Overview**
 - There has historically been a gap in mortality rates between the top four most common cancers and rare and less common cancers
 - Cancer52 is concerned that that gap could widen following the pandemic. NHS England should disaggregate waiting times figures and any other recent datasets for a) common cancers b) rare and less common cancers to identify if there is a gap or not
 - The National Cancer Board should review whether any groups have been particularly adversely affected by the impact of Covid-19

- **Reassurance**
 - In order to ensure that people with rare and less common cancer get the treatment they need, the NHS should work to reassure people that it is safe to go back to treatment
 - NHS England should continue to encourage people back to the NHS via its recent 'helpshelpyou' campaign. It is particularly important that people who think they might have cancer present in primary care
 - Cancer52's survey showed that people with rare and less common cancer are as anxious about Covid-19 as their cancer. The NHS should publish figures on how many people with cancer have had Covid-19, along with mortality rates. It should conduct a rapid review into the risks Covid-19 poses to people with cancer. This should then inform treatment protocols and shielding advice
- **Shielding**
 - Cancer52's survey found that while some people had coped with shielding, others had found it difficult and were worried about shielding ending
 - There needs to be support for people's mental health, particularly loneliness. Everyone who has been shielding should be offered a consultation with their GP regarding counselling
 - Government communications should reiterate the importance of socially distancing to support the most vulnerable. It should consider introducing a badge scheme similar to the 'baby on board' scheme used on public transport
 - People who have been shielding need support to return to work, NHS care and get their lives back. People who have been shielding should be able to remain on furlough as long as necessary
- **New ways of working**
 - It was positive that many people in Cancer52's survey had had telephone or online appointments during the pandemic. There should be clear protocols for telephone and video consultations, produced with patients
 - Existing NHS surveys (NCPES, GP survey) should incorporate questions about the experience of having telephone and video consultations
- **Support for charities**
 - Many people with rare and less common cancer turned to patient support groups and cancer charities for support during the pandemic. Cancer52's member survey showed that many members are facing financial difficulties. Government should support cancer patient support groups financially
- **In event of second wave**
 - Cancer treatment and care should continue. There needs to be an analysis of any variations that arose during the first wave, so that they can be mitigated in any second wave
 - Communications to people who are shielding need to be prompt, timely, clear and evidence based.

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