Cancer52

Submission to Kruger review on sustaining the community response to the Coronavirus crisis

22 July 2020

1. Introduction

1.1. Cancer52 welcomes the opportunity to submit evidence to this review into how the community response to the Coronavirus crisis can be sustained.

2. Cancer52

2.1. Cancer52 is an alliance of nearly 100 predominantly small patient support group charities working to address inequality and improve outcomes for people with rare and less common cancers. Rare and less common cancers are all those that are not included in the group of the four most common cancers - bowel, lung, prostate and breast.

2.2. Every year, about 144,600 people in England are diagnosed with a rare or less common cancer - cancers such as testicular, leukaemia, sarcoma and pancreatic. Although fewer people are diagnosed with these cancers than the four most common cancers, more people die from these cancers: 74,500 people every year. In fact, 47% of the cancers diagnosed in 2017 in England were rare or less common cancers but 55% of the deaths from cancers were from these conditions.

2.3. To inform this submission Cancer52 has used the findings of two online surveys of its charity members - one in early April 2020 and one in early May, an online survey of over 1,000 people with rare and less common cancers in England in July 2020, and has discussed the issues facing people with rare and less common cancers and our member organisations at regular virtual meetings throughout the coronavirus crisis. Several members have also shared the findings from surveys of the people they support with us and provided other forms of evidence.

3. Key headlines

3.1. Cancer52 commends the efforts of all those working in health and social care to tackle, contain and treat Covid-19. Cancer52 and its members understand that these are unprecedented and challenging times for everyone - including those working in Government, those working on the front line and those living with cancer. Cancer52 and its members are working to support people with rare and less common cancers and the NHS and social care sector to ensure people with cancer can continue to be diagnosed, supported, and treated during the immediate crisis and during recovery and restoration of services. However, Cancer52 is concerned about the impact on people with rare and less common cancers and the charities that support them.
4. **Impact on people with rare and less common cancers**

4.1. People with rare and less common cancers have experienced several challenges during the coronavirus crisis:

- Referrals for cancer have dropped during the Coronavirus crisis as people have been nervous to come forward with symptoms that could be cancer. Cancer52 is concerned that this means fewer people with rare and less common cancers are being diagnosed and that the opportunity for early diagnosis and therefore lifesaving treatment, has been missed.
- Some people with rare and less common cancer have had their treatment paused or halted - for example, palliative treatment stopped, surgery pushed back or immunotherapy interrupted. Of those respondents to our online survey who were undergoing treatment, or were about to start, a quarter had faced changes of some kind including delays and cancellations. While this is causing anxiety among patients, particularly with concerns about cancer progressing, people are also worried about the dangers of coming into hospital for tests and treatment while the pandemic is ongoing.
- New clinical trials have been halted due to the coronavirus crisis. Some patients were withdrawn from existing trials due to concerns about their safety. For some patients, participating in clinical trials offer their only opportunity for treatment. Of the 67 people who responded to our survey who were participating in a clinical trial, a third had seen their trial paused, ended or they were removed.
- Cancer52 estimates that around 100,000 people with rare and less common cancer have been told to shield themselves. 70% of the people who responded to our survey had been told to shield. People told us that the language and communication around shielding, isolating and social distancing has been confused, leaving people unsure which group they belong to and what action they should be taking, and that it had been difficult to access help at the beginning of the pandemic. This has continued with the recent announcement that shielding will be ending.

5. **Support from charities and patient groups**

5.1. The impact of cancer is wide ranging with many people with rare and less common cancers facing physical, emotional, practical and financial issues. Some of these are long lasting. People require a variety of different types of support from physiotherapists to benefit advisers, from counselling to speech therapists. People with rare and less common cancers can often find it difficult to access suitable support due to the less common or rare nature of their condition. Many rely on support groups or patient charities with the expertise to help. In some cases, our member patient groups are the only such organisations providing specialist support and information.

5.2. Support services for people with rare and less common cancers have been impacted by the coronavirus. Face to face support and support groups have had to stop. Other forms of support could not be accessed during this time. A quarter of respondents to our patient survey use support services regularly. Of these one in five had seen such services stopped and had not been able to find help elsewhere. Two out of five of these people have accessed services elsewhere, less frequently or in a different way.
5.3. Our members tell us that some Clinical Nurse Specialists (CNS) and other members of the clinical team were deployed to care for Covid patients. This means that some people with rare and less common cancers did not have the support or information they needed, with some patients not able to reach clinical teams with queries about recurrences or complications. One in ten people who tried to contact their cancer team during the pandemic had been unable to reach anyone. In our online patient survey, people told us that they 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. Our members have seen an increase in demand for their services. Often queries are related to coronavirus because advice and support from the healthcare system has not been available.

6. Impact on charities

6.1. Covid-19 has had a significant impact on rare and less common cancer charities. A survey of Cancer52 members found that a majority had seen a drop in income, and they are worried about their long-term future. Losing charities that represent and support people with rare and less common cancers would weaken the patient voice, which is crucial for informing NICE and industry, and cut the support available to people with rare and less common cancers. As one of our members highlighted, losing patient groups would have a ‘detrimental impact on the provision of essential services currently available for rare and less common cancers as well as effectively silencing the voice’ of these people.

6.2. Member charities have recorded increased demand for their information and support lines, reflecting concerns among patients about Covid-19. Our members are providing support and advice to patients because NHS services are not currently able to do this. In a recent survey of charity members, two thirds of respondents said demand for their services had increased - about a third had seen demand increase by more than 50%. However this work is not funded and the ability of members to fundraise has been dramatically hindered by the lockdown and social distancing restrictions. Seven in ten respondents to our survey had seen their income hit by the coronavirus, with some reporting drops of over 50% and others expecting income to fall in the future. The majority of Cancer52 members (more than 60) have an income of below £500,000. Cancer52 has already offered to waive donations from its members for the coming financial year to ensure that it supports its member charities at this extremely difficult time and ensures that the voice of people with rare and less common cancers remains heard.

6.3. Only three of our member charities surveyed have been able to access government funding. It is vital that frontline organisations, including Cancer52 members, are able to access funding quickly and easily. We are concerned that the £360 million given to central Government departments via a process that lacked transparency and has already been distributed and it is unclear how the National Lottery Funding will be allocated. The Select Committee for the Department of Culture, Media and Sport’s recent report, The Covid-19 crisis and charities, called for more transparency on how these funds are operating, as well as a stabilisation fund for the charity sector to ensure its survival.

6.4. The majority of our members operate on a national level with no or limited local presence. This is because they support rare and less common communities of patients often scattered across the country with no access to local specialist support. For many of these people our charity members provide the only source of specialist support and information. However, Government support during the pandemic has often been focused on local and neighbourhood geographic aspects of community groups and charities, completely failing to recognise the vital work small charities such as our members have also been contributing during these difficult times and under considerable strain. Such organisations must not be forgotten.
7. **Working with the NHS**

7.1. Throughout the Coronavirus crisis, the cancer charity community has worked closely with colleagues in the NHS and the Cancer Team within NHS England to share intelligence and to ensure patients are receiving the accurate and timely information they need. The NHS England Cancer Team has hosted weekly online meetings with charities to disseminate the latest advice and to answer charities’ questions. It has been a very useful exchange - allowing charities to raise the issues their patients are facing with the team responsible for national cancer policy and delivery. Cancer52 and its members would like to see these meetings continue in some regular form until cancer services have fully recovered.

7.2. NHS England has also worked with cancer charities to produce a written Frequently Asked Questions document that has been updated and disseminated to member charities by Cancer52 throughout the crisis. This has ensured consistency of messaging and allowed cancer charities confidence that they are giving the people they support the most up-to-date advice.

7.3. To help reassure people with rare and less common cancers that it is safe to come forward for diagnosis and treatment, Cancer52 with its members produced a video featuring people with rare and common cancers sharing their experiences of going into hospital during the pandemic. This video was shared by NHS England and the National Clinical Director for cancer, Professor Peter Johnson, featured in the video.

8. **Recommendations**

8.1. The Government should ensure that its definition of small charities is not defined by solely geographic terminology thereby excluding small charities who provide an invaluable service supporting the NHS at a national level.

8.2. The Government must ensure that rare and less common cancer charities, particularly those that provide frontline support, are able to access funding.

8.3. NHS England should continue its regular communication with the cancer charity community as the NHS restores services.

8.4. NHS England, Cancer Alliances and NHS services must restart all cancer services as quickly and as safely as possible. This will mean ring fencing diagnostics capacity for cancer services and ensuring Covid-19 free facilities with the testing resources to support this.

8.5. The public and current patients must be made aware that the NHS can continue to treat people with cancer safely. People with symptoms must be encouraged to come forward. This may require an urgent national information campaign to ensure the message reaches the public.

For further information on this briefing, please contact: Jane Lyons, CEO, Cancer52, info@cancer52.org.uk