

**Cancer52 Submission to Health and Social Care Select Committee Inquiry:  
Delivering Core NHS and Care Services during the Pandemic and Beyond.  
Impact of Covid-19 on People with Rare and Less Common Cancers  
Monday 27 April 2020**

## **Cancer52**

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.

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.

## **Key headlines**

**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 these times. This is important considering the Coronavirus pandemic is likely to continue for some months to come. However, Cancer52 is concerned about the impact on people with rare and less common cancers and the charities that support them.**

## **Impact on people with rare and less common cancers**

- Cancer52 estimates that around 100 000 people with rare and less common cancer have been told to shield themselves. However, Cancer52 is concerned that not all patients who should have received a shielding letter have done so. Patients self-reporting on the Government's website are being rejected by automated email.
- 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. The advice to contact a patient's medical team regarding the need to shield is not always appropriate. Many cancer nurse specialists (CNS) have been re-deployed, making it very difficult to reach clinical teams during this time. Local teams such as GPs and Practice Nurses do not always have the

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knowledge and understanding regarding rare and less common cancers to give reliable advice.

- Cancer52 and its members are concerned about the impact of the response to Covid-19 on the early diagnosis and screening of cancer. Screening programmes have been paused or significantly scaled back. Presentations for diagnosis have decreased significantly as members of the public appear reluctant to come forward at this time.
- Cancer52 is concerned that treatment for rare and less common cancer is being postponed or cancelled. This includes surgery and treatments, that while not curable, offer prolonged extension to life.
- Member charities are concerned about the short and long-term psychological and emotional impacts of the coronavirus pandemic on people with rare and less common cancers and their families, particularly if they cannot access support and/or their treatment is delayed. CNSs are being deployed to the front line, meaning patients have lost their point of contact and support.
- Member charities are concerned that people nearing the end of their lives are not accessing the high quality support they need. We understand that some palliative treatment for patients may have been stopped because of the risks involved.
- Cancer52 is also concerned about the impact of Covid-19 on the delivery of the Cancer Programme. Our recent policy report, *Getting a Better Deal: One Year on from the NHS Long-Term Plan*, outlined where there was good progress and where progress could be improved up until the point that the pandemic hit.<sup>1</sup>

### Impact on charities

**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. If any charities that represent and support people with rare and less common cancers were to disappear in the future, that would have a significant detrimental impact on ensuring the patient voice is heard and the support available to people with rare and less common cancer would be diminished.**

- Member charities have recorded increased demand for their information and support lines, reflecting concerns among patients about Covid-19, yet their ability to fundraise has dramatically fallen. In a recent survey of members, 85% of respondents said demand for their services has increased. The majority of respondents to our survey had also seen their income hit by the coronavirus, with some reporting drops of over 50%. The majority of Cancer52 members have an income of below £500 000.
- Member charities that fund nurses and healthcare professionals report that these staff members have been redirected to support Covid-19 efforts, taking them away

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<sup>1</sup> <https://www.cancer52.org.uk/single-post/2020/04/08/Getting-a-Better-Deal-for-Rare-and-Less-Common-Cancers---One-Year-on-from-the-NHS-Long-Term-Plan>

from supporting people with rare and less common cancer. These charities are therefore supporting the Covid-19 frontline with workforce and other resources, which have been charitably funded.

- Some of our members also support clinical research and this has been paused. It may be difficult to restart some clinical research because jobs may have been lost.
- Cancer52 welcomed funding for the charitable sector announced by HM Treasury on 7<sup>th</sup> April. However some three weeks later at time of writing, it is still not clear how the £750 million of funding will be distributed. It is vital that frontline organisations, including Cancer52 members, are able to access this funding quickly and easily. We are concerned that the £360 million given to central Government departments has already been distributed and that the National Lottery Funding will be for local charities. Many rare and less common charities, though small, operate nationally, in order to give the best support to people affected. In particular, people with rare and less common cancers may need the support of a national charity as there may not be anyone locally with knowledge of their cancer who can provide support.

#### Recommendations

- **The National Cancer Board should meet to review progress against the Cancer Programme before its scheduled meeting in June. This will allow the Board to take action to mitigate any detrimental effects of Covid-19 on cancer services.**
- **The Government must ensure that rare and less common cancer charities, particularly those that provide frontline support, are able to access funding.**
- **The Government must clarify shielding arrangements for patients.**

#### Questions to ask

- **How does NHSE intend to manage the increase in demand for cancer services when cancer services return to normal and/or people present again for diagnosis?**
- **How are the cancer hubs operating?**
- **What percentage of cancer treatment and care has been delayed?**
- **Are there particular cancer types where treatment has been delayed more than others?**
- **Are there any drugs that should be brought onstream now because they can be given at home or replace treatment delivered in hospitals?**
- **How is NHSE ensuring safeguarding of people being treated virtually?**
- **When and how can research restart?**

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

**Cancer52 Submission to Health and Social Care Select Committee Inquiry:  
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Impact of Covid-19 on People with Rare and Less Common Cancers**

**Thursday 7th May 2020**

**1. Introduction**

Cancer52 welcomes the opportunity to submit evidence to the Health Select Committee inquiry into delivering core NHS and care services during the pandemic and beyond. This submission follows our shorter contribution submitted on Monday 27th April 2020 and provides more evidence and detail.

**2. Cancer52**

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.

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<sup>1</sup>. 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<sup>2</sup>. 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<sup>3</sup>.

To inform this submission Cancer52 has undertaken two online surveys of its members - one in early April and one in early May, 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**

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

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<sup>1</sup> 144,642 were diagnosed with a rare or less common cancer in 2017 PHE/NCRAS May 2019

<sup>2</sup> 74,416 died from a rare or less common cancer in England in 2017 PHE/NCRAS May 2019

<sup>3</sup> <https://www.ndrs.nhs.uk/wp-content/uploads/2019/05/FINAL-SHARE-SLIDE-DECK-Development-in-data-for-rare-and-lesscommon-cancers-220519.pdf>

diagnosed, supported, and treated during these times. This is important considering the Coronavirus pandemic is likely to continue for some months to come. However, Cancer52 is concerned about the impact on people with rare and less common cancers and the charities that support them.

#### **4. Impact on diagnosis**

People with rare and less common cancers are usually diagnosed with their condition following an initial GP consultation, following a visit to accident and emergency or via a screening programme. A survey of people with rare and less common cancers conducted by Cancer52 in 2018 found that people with rare and less common cancers already find it difficult to gain a diagnosis when the health and social care system is operating under normal circumstances<sup>4</sup>. The often vague nature of their symptoms and a lack of awareness among health professionals and the general public mean symptoms can be dismissed and people may need to visit their GP several times before a diagnosis is obtained. At present people are nervous to visit their GP or A&E due to fears about Covid-19.

Cancer52 is concerned that this means fewer people with rare and less common cancers are being diagnosed. Early diagnosis of cancer is important as it can lead to more effective treatment and better survival. People are still developing cancer during this pandemic but they may be diagnosed at a later stage of their cancer, limiting their treatment options and survival chances.

In evidence presented to the committee on Friday 1st May 2020, Dame Cally Palmer, National Cancer Director, confirmed that referrals for cancer had fallen during the period of lockdown. In the week commencing 25th April 2020 referrals under the two week wait pathway were 62% lower than for the same period in 2019. In addition, the number of people visiting A&E departments has also fallen (30% fewer visits in March 2020 compared to March 2019<sup>5</sup>). Screening programmes have also been halted temporarily. Some of our member organisations are hearing anecdotally that the number of diagnoses for certain cancers are lower than normal.

As diagnoses are delayed at present, this presents the possibility of a surge of new potential cancer patients coming forward when people feel it is safe to do so and an overstretched system may become overwhelmed. Concerns about diagnostics capacity and workforce already existed before the Covid-19 crisis and additional demands and complications threaten to amplify this.

It is vital that the health service provides a safe way for cancer patients to gain access to diagnostics testing as quickly as possible. Diagnostics capacity must be ring fenced for cancer and the government must make it abundantly clear to people that they should come forward if they suspect they may have cancer or are experiencing unusual symptoms, and that it is safe to do so. Now more than ever is the need to solve some of the diagnostics issues that have plagued cancer services and to plan for any potential surge in people coming forward.

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<sup>4</sup> <https://www.cancer52.org.uk/single-post/2019/07/10/Getting-a-better-deal-for-people-with-rare-and-less-common-cancers-what-we-can-learn-from-patients>'-1

<sup>5</sup> <https://www.england.nhs.uk/statistics/statistical-work-areas/ae-waiting-times-and-activity/ae-attendances-and-emergency-admissions-2019-20/>

## 5. Impact on treatment

Cancer52 is reassured that NHS England and Cancer Alliances have established Cancer Hubs in order to ensure Covid-19 free capacity for cancer surgery. This must be extended to include other forms of treatment as quickly as possible. Our members are hearing varied accounts from people with rare and less cancer about their treatment being paused or halted. For example, the treatment of children appears unaffected while other patients have had their palliative treatment stopped, surgery pushed back or immunotherapy interrupted. In some cases treatment plans are being changed without a conversation about this with the patient themselves. 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. For example a survey by Kidney Cancer UK found that of people waiting for surgery, 17% would decline if offered a date now, 35% would accept and 48% were unsure<sup>6</sup>. Cancer52 would like more information about how Cancer Hubs are operating and whether all rare and less common cancers are covered by them.

Cancer52 also understands that there may be regional variation, with those areas most impacted by coronavirus not having the capacity to offer a full cancer service, while other areas not impacted as badly able to provide fuller services. Capacity should be looked at across the whole health and social care system so that people living in certain areas are not disadvantaged.

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. We were therefore heartened to hear from Dame Cally that NHS England hopes to get recruitment for new trials back up and running in May.

Patients must be reassured that it is safe for them to have treatment. This will require the ability to test patients in advance of coming to the Covid-19 free hubs and the capacity to regularly test staff members. Complementary to this, clinicians should be exploring ways for patients to receive treatment at home where appropriate, ensuring there is the specialist capacity in place to support this.

## 6. Impact on support

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 patients charities with the expertise to help.

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 cannot be accessed during this time. Members tell us that some Clinical Nurse Specialists (CNS) and other members of the clinical team have been deployed to care for Covid patients. This means that some people with rare and less common cancers do not have the support or information they need, with

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<sup>6</sup> <https://www.kcuk.org.uk/the-impact-of-covid-19-on-kidney-cancer-patients/>

some patients not able to reach clinical teams with queries about recurrences or complications. People are instead turning to our member charities, and our members are therefore seeing 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.

This is a particularly difficult time for those people with rare and less common cancers. Many have been asked to shield, others have had to change their treatment plans, and some have been affected financially. People are relying on patient groups and charities because support from health and social care services is reduced or not accessible. We are concerned about the long term impact of this crisis on the emotional and mental wellbeing of people with rare and less common cancers, who can find it harder to access patient groups and support.

While it is vital that cancer diagnostics and treatment are restarted as quickly as possible, it is equally important that the NHS support services that run alongside these are also restored. People should not be left in a situation where they are struggling to cope with the impacts of their cancer, impacts that have often been amplified during this crisis.

## **7. Impact on end of life care**

Each year 74,500 people with a rare or less common cancer die from their condition. These people deserve high quality care and support at the end of their lives. Cancer52 is concerned about the impact of coronavirus on such support. Hospices and community services have been particularly hard hit by the crisis with difficulties accessing PPE. We are also aware that palliative treatment for some patients has been stopped.

People with rare and less common cancers have also expressed concerns that they won't be prioritised for treatment if they were to develop coronavirus. All patients should be treated as individuals with their end of life care choices discussed sensitively with them. No blanket assumptions should be made.

## **8. Impact on workforce**

The cancer workforce was already stretched when the coronavirus crisis struck, particularly in diagnostics. The number of cancer cases has been increasing, placing growing demand on the system. Cancer charities were dissatisfied with the plans drawn up to address these challenges and had made their concerns known. The health and social care workforce has faced extreme pressure during this pandemic with many deployed to work in new areas, many becoming ill with the virus and some losing their lives or their colleagues. A survey of healthcare workers found that 1 in 3 said that their physical health had got worse during the crisis<sup>7</sup>.

Cancer52 stresses the need for investment in our health and social care workforce. Now more than ever we must work to address workforce shortages and pressures, particularly in cancer and particularly in diagnostics. Support must be provided for those working on our frontline to tackle coronavirus, cancer and the myriad of other conditions impacted by this pandemic. Our health and social care service faces ongoing challenges for several months to come and if it is to be fit for

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<sup>7</sup> Macmillan Cancer Support

purpose, providing high quality care for all patients and saving lives, we must have the right professionals in place with the right skills and experience. This is even more vital in rare and less common cancers where there may be only a handful of medical and clinical nurse specialists with this knowledge and who we cannot afford to lose. This requires an aggressive and proactive plan both short and long term.

## **9. Shielding**

Cancer52 estimates that around 100 000 people with rare and less common cancer have been told to shield themselves. However, Cancer52 is concerned that not all patients who should have received a shielding letter have done so. Patients self-reporting on the Government's website are being rejected by automated email. It is unclear who is making these rejection decisions and on what basis. Cancer52 would welcome greater transparency and clarity about the online process to reassure our members and patients alike that the process is fair and robust.

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. The advice to contact a patient's medical team regarding the need to shield is not appropriate. For example, Laryngectomy patients who face speech and language difficulties were told this despite their disability and the challenges this posed. Many CNSs have been re-deployed, making it very difficult to reach clinical teams during this time. Local teams such as GPs and Practice Nurses do not have the knowledge and understanding regarding rare and less common cancers to give reliable advice. More must be done to simplify the communication around shielding and to remove the confusion that exists. A confirmation to the public when all shielding letters have been sent would reassure people they have not been missed.

## **10. Impact on charities**

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 and cut the support available to people with rare and less common cancer. 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.

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. However this work is not funded and the ability of members to fundraise has been dramatically hindered by the lockdown. In a recent survey of charity members, 85% of respondents said demand for their services has increased. The majority of respondents to our survey had also seen their income hit by the coronavirus, with some reporting drops of over 50%. The majority of Cancer52 members have an income of below £500,000.



Honorary President: Baroness Morgan of Drefelin | Chair: Jonathan Pearce | CEO: Jane Lyons  
Board: Lindsey Bennister, Helen Morement, Rebecca Porta, Nic Puntis, Rebecca Rennison, John Symons, Christopher Walden

Cancer52 welcomed funding for the charitable sector announced by HM Treasury on 7th April. However some weeks later, at the time of writing, it is still unclear how the £750 million of funding will be distributed. In a recent survey of our members, 8 out of 9 had not been able to access government funding. It is vital that frontline organisations, including Cancer52 members, are able to access this funding quickly and easily. We are concerned that the £360 million given to central Government departments has already been distributed and unclear how the National Lottery Funding will be allocated. The Select Committee for the Department of Culture, Media and Sport 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<sup>8</sup>.

## 11. Recommendations

- **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.**
- **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.**
- **Gaps in the cancer workforce must be urgently reassessed and addressed. Now more than ever is the time to invest in, and support, our health and social care workforce.**
- **NHS Services that support people with rare and less common cancers with the effects of their condition must also continue to operate.**
- **The National Cancer Board should meet to review progress against the Cancer Programme before its scheduled meeting in June. This will allow the Board to take action to mitigate any detrimental effects of Covid-19 on cancer services.**
- **The Government must ensure that rare and less common cancer charities, particularly those that provide frontline support, are able to access funding.**
- **The Government must clarify shielding arrangements for patients.**

**For further information on this briefing, please contact: Jane Lyons, CEO, Cancer52, [info@cancer52.org.uk](mailto:info@cancer52.org.uk)**

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<sup>8</sup> <https://committees.parliament.uk/work/243/impact-of-covid19-on-the-charity-sector/publications/>