

Written evidence from Macmillan Cancer Support (COV0216)

1. Macmillan Cancer Support is a registered charity providing information and support for people with cancer. Macmillan plays a key role in supporting the NHS workforce. Over the past ten years Macmillan has invested £386 million in the NHS. Macmillan funds nearly 12,000 Macmillan nurses, doctors and other health professionals.

2. Executive Summary

- 2.1. Prior to COVID-19 crisis the NHS was already showing strain with an extra 1.4 million people a year are being referred for cancer tests compared to 2010. That's almost 2.5 times the number of patients, causing relentless pressure on a desperately overworked workforce. The 62-day cancer waiting times target first started to be frequently breached over six years ago and it has now been missed continuously for over four years (53 months in a row), since January 2016.¹
- 2.2. Macmillan accepts it may have been appropriate to delay or alter normal treatment protocols on a clinical basis because of an individual's risk of contracting COVID-19. There may also have been decisions made based on capacity. This has resulted in thousands of people having their cancer care disrupted.
- 2.3. Disruption to treatment may have a significant impact on those patients awaiting treatment and care. It is essential that the Government does all it can to ensure that the NHS has everything it needs to address the backlog swiftly and safely. We are also concerned that disruption to care may exacerbate existing inequalities within the system.
- 2.4. Macmillan has been calling for an urgent recovery plan for NHS cancer services since April, to ensure cancer does not become the forgotten 'C'. The Department of Health and Social Care must now urgently commit to publishing a recovery plan to address the backlog, including the allocation of staffing and resources needed to deliver the safest possible care.
- 2.5. Macmillan has long understood that cancer represents not only a health crisis but also the risk of financial hardship. And during the pandemic we have become increasingly concerned that many have had to decide whether to prioritise their health or risk financial disadvantage and potentially be discriminated against if they are shielding.

3. Introduction

- 3.1. Under the Equality Act 2010, when a person is diagnosed with cancer, they are automatically classified as disabled for the purposes of the Act. This protection from discrimination continues even when there is no longer any evidence of the cancer.
- 3.2. The national COVID-19 response is directly affecting thousands of people with cancer. Across the UK we estimate up to 240,000 people with cancer² fall into the 'clinically extremely vulnerable' classification because of their specific type of cancer or their treatment regime. This means they should have been contacted about 'shielding'.
- 3.3. Other people with cancer who don't fall into the above list may also be at high risk because of their age. Two thirds of people living with cancer in England are over 65. This group are at

¹ NHS England, [Cancer Waiting Times — National Time Series Oct 20019 — Jan 2020 with Revisions](#).

² NHS England and NHS Improvement estimated in mid-March that 200,000 people with cancer needed to be contacted about shielding because they were deemed to fall into the 'clinically extremely vulnerable' classification in England, which Macmillan estimates if a similar ratio to incidence in 2017 applied across the UK, it could equate to around 240,000 'clinically extremely vulnerable' people in the UK. Since this estimate was made additional people living with cancer may have been identified as 'clinically extremely vulnerable'.

higher risk of severe complications if they contract COVID-19, even if they don't fall into the 'Clinically extremely vulnerable' category.

- 3.4. Macmillan is concerned that the response to COVID-19 is having an undue impact on people living with cancer and as a protected characteristic this should be considered.
- 3.5. The human rights issues facing people living with cancer that have arisen during this pandemic range from access to cancer treatment, the impact on screening and many being forced to choose between protecting their health and suffering further economic hardships.
- 3.6. The response from Government and across public services has had, and will continue to have, a profound impact on all aspects of people living with cancer. Therefore, it is vital that people living with cancer are given consideration in current and future plans. The Government must ensure that cancer does not become the 'forgotten C' whether in health and care, with job security or having a financial impact on people living with cancer due to their cancer diagnosis.

3. Cancer Treatment

- 3.1. Macmillan accepts it may have been appropriate to delay or alter normal treatment protocols. However, these decisions should be agreed on an individual basis and determined by clinical and practical considerations about the risks and benefits of treatment for each patient and not through blanket suspensions due to concerns about system capacity.
- 3.2. Macmillan are concerned that changes in treatment may exacerbate existing inequalities. We already know that people with cancer in England receive less surgical treatment in the most deprived areas (40%) than the least deprived areas (48%).³
- 3.3. In addition, people with cancer who are Black or Asian are 24%-36% more likely than those who are White to say their treatment options were only partially explained or not at all before they started treatment. People with cancer who are Black or Asian are 41-48% more likely than those who are White to say they were only partially involved in decisions about their care and treatment.⁴
- 3.4. Blanket suspension of services may result in poorer clinical outcomes for people with cancer. We do not believe this to be an acceptable trade off. It could also create more pressure on the health system in the longer term when it tries to 'catch up' and requires additional, 'surge' capacity to do so in a timely way.
- 3.5. Despite the clear directives that providers should continue to prioritise cancer treatment, we are aware of some instances where blanket cancellations of surgery, chemo/radiotherapy and screenings have taken place, which may be in contravention of this guidance. Whilst we understand the need to make sure that the NHS has capacity to deal with the COVID-19 pandemic, delaying cancer treatment will have real negative consequences not only for patient outcomes but for NHS staff by building up demand for cancer services in the future. A significant backlog in the system is emerging at a time when cancer waiting times are already at historical highs.
- 3.6. For some patients, if their cancer is not treated in a timely way, it may reduce their chances of survival. This is especially the case for cancers which may grow and metastasise in the timeframe where their treatment is delayed. A study published by UCL and DATA-CAN has

³ Public Health England. 2018. Seven things we learned from our latest cancer treatment data.

<https://publichealthmatters.blog.gov.uk/2018/07/17/seven-things-we-learned-from-our-latest-cancer-treatment-data/>

⁴ NHS England. 2019 National Cancer Patient Experience Survey for England. <https://www.ncpes.co.uk/2019-national-level-results/>

already predicted a 20% increase in cancer deaths due to the COVID-19 pandemic⁵. It is clear that the delay or cancellation of treatment may have a significant effect on those patients awaiting treatment and care. It is essential that the Government does all it can to ensure that the NHS has everything it needs to address the backlog swiftly and safely. When restoring cancer services, this should also tackle inequalities experienced by people living with cancer.

- 3.7. Additional resources may be required to address the backlog caused by the COVID-19 disruption. There should be support in place to meet people's emotional and physical needs whilst they're waiting for care.
- 3.8. The number of people in England starting treatment for cancer dropped to 16,678 in May 2020. Under normal circumstances we would have expected this figure to have been around 25,700, which means the number of people starting treatment is around 9,000 lower than we would have expected for May 2020⁶— a drop of 35%. The difference against expected figures is around three times as large as it was last month (11%).
- 3.9. In addition, the number of people having surgery as a subsequent treatment for cancer dropped to 3,891 in May 2020. This is a 13% drop from what we would have expected for May 2020.⁷
- 3.10. As of May 30th, there were more than 180,000 people in England waiting for an endoscopy - a rise of 44% from the same time in 2019. And of these people, 66% are waiting six weeks or longer for these vital tests.⁸

4. Impact on referrals and screening

- 4.1. Some parts of the country are seeing a rapid decline in referrals to investigate suspected cancer by as much as 75%.⁹ This means 94,000 fewer people saw a specialist for suspected cancer following an urgent GP referral, than during the same period last year. As thousands of these 'invisible patients' are diagnosed with cancer and begin their treatment, our cancer services face being under more pressure than ever before.¹⁰
- 4.2. In addition A&E attendances have fallen by up to 60%.¹¹ Under normal circumstances, we would expect around 1 in 5 (19%) cancer diagnoses in England to take place following an emergency presentation¹², and cancer patients in England to have an average of 3 emergency admissions in their last year of life.¹³ Prior to COVID-19 we were already concerned that people with cancer in the most socio-economically deprived areas in England are 20% more likely to have their cancer diagnosed at a late stage than people in the least deprived areas.¹⁴
- 4.3. The effect of a short-term drop in urgent 'two-week wait' referrals is likely to result in more people being diagnosed at a later stage, which may reduce the chances of survival. With reduced diagnostic capacity (as COVID infection measures reduce productivity), this also could lead to even longer waiting times, when the crisis eases off. Before COVID-19, NHS England

⁵ UCL & DATA_CAN, 29th May - [Deaths in people with cancer could rise by at least 20%](https://www.data-can.org.uk/latest/deaths-in-people-with-cancer-could-rise-by-at-least-20/) <https://www.data-can.org.uk/latest/deaths-in-people-with-cancer-could-rise-by-at-least-20/>

⁶ NHS England. [Cancer Waiting Times — National Time Series Oct 2009 –May 2020 with Revisions](#)

⁷ Ibid, The number of people starting treatment generally follows a predictable trend and has been increasing slightly year-on-year for several years. For May 2020 we believe the most appropriate comparison is the figures for May 2019

⁸ Monthly Diagnostic Data 2020-21, NHS England and NHS Improvement

⁹ <https://scienceblog.cancerresearchuk.org/2020/04/21/how-coronavirus-is-impacting-cancer-services-in-the-uk/>

¹⁰ NHS England. [Cancer Waiting Times — National Time Series Oct 2009 –May 2020 with Revisions](#).

¹¹ <https://nhsproviders.org/confronting-coronavirus-in-the-nhs/5-what-next-the-future>

¹² Based on figures from 2016. Public Health England. Routes to Diagnosis. Available from: <http://www.ncin.org.uk/view?rid=3759>

¹³ Marie Curie. Emergency Admissions Report 2018. Available from:

<https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2018/emergency-admissions-report-2018.pdf>

¹⁴ Lyratzopoulos, G et al. 2012. Socio-demographic inequalities in stage of cancer diagnosis: evidence from patients with female breast, lung, colon, rectal, prostate, renal, bladder, melanoma, ovarian and endometrial cancer. <https://academic.oup.com/annonc/article/24/3/843/207310>

Cancer Waiting Times performance was at the worst ever level recorded therefore COVID-19 recovery is likely to exacerbate pre-existing delays.¹⁵

- 4.4. The number of people in England starting treatment for cancer following urgent GP referral for suspected cancer specifically (i.e. excluding those diagnosed through other routes, e.g. cancer screening) dropped to 8,564 in May 2020. Under normal circumstances we would have expected this figure to be around 13,800, which means the number of people starting treatment following an urgent GP referral for suspected cancer is around 5,000 lower than we would have expected for May 2020— a drop of 38%. The difference against expected figures is almost three times as large as it was last month (14%).¹⁶
- 4.5. Health inequalities have become even more apparent during COVID-19. Those from deprived backgrounds are more likely to be diagnosed through emergency routes to diagnosis, be diagnosed later and more likely to develop cancer earlier in their life. The increases in cancelled or delayed treatment and reduced numbers visiting A&E may potentially affect access for more deprived people with cancer leading to more severe physical and emotional needs.
- 4.6. Screening programmes – for bowel, breast and cervical cancer – have been paused during the pandemic. The number of people in England starting treatment for cancer following a cancer screening referral dropped to just 551 in May 2020 from 1,748 in May 2019 — a drop of 69% compared with last year.¹⁷

5. Shielding

- 5.1. Throughout the COVID-19 crisis Macmillan has heard from people with cancer that they wanted more clarity and information from the Government about shielding.
- 5.2. Macmillan's Telephone Buddies scheme, which was created to support people living with cancer during COVID-19, matches volunteers with cancer patients so they can arrange to have regular chats with someone about what they're going through. In addition to our free Support Line and Online Community remain valuable sources of virtual support.
- 5.3. Macmillan commissioned a poll of people living with cancer in June. This found that (19%) of people reported they have barely left the house because they're scared to do so, and (9%) have experienced panic or anxiety attacks or even suicidal thoughts because of the virus.
- 5.4. One in five (20%) of those who have not left the house at all since the start of lockdown say they won't feel safe enough to do so until a vaccine or effective treatment is widely available irrespective of changes to recent government shielding guidance
- 5.5. Macmillan's services reported many people with cancer who were identified as high-risk of COVID-19 and advised to 'shield' experienced issues accessing the Government's Job Retention Scheme. Our Support Line received calls from people who are unable to undertake available work due to shielding, whose employers are not offering furlough but instead encouraging them to be signed off sick, which puts them at a significant financial disadvantage. We are also aware of people with cancer being asked to claim sick pay while colleagues in equivalent positions are offered furlough. People with cancer should not be put at a financial disadvantage and discriminated against if they are shielding.

¹⁵<https://medium.com/macmillan-press-releases-and-statements/macmillan-responds-to-january-2020-cancer-waiting-times-bb1dd7e98f26?source=-----0----->

¹⁶ Ibid.

¹⁷ NHS England. [Cancer Waiting Times — National Time Series Oct 2009 –May 2020 with Revisions](#). In May 2019 the figure was 200,599.

- 5.6. The Office for National Statistics (ONS) has shown that of the 627,000 shielded people who were working before being advised to shield, 5% continue to work outside the home, despite being advised not to leave home.¹⁸ Of those who continue to work outside the home, an estimated 19,000 would be unable to meet their financial obligations if they stopped working. Of those who are not currently working, 36% have been furloughed, but 17% have stopped working altogether.
- 5.7. Equalities legislation protects people with cancer from discrimination at work. There is a duty on employers not to treat employees with cancer less favourably than other people who do not have cancer, and to make 'reasonable adjustments to support someone with cancer to stay in work. Employers should consult with employees about any adjustment and involve them at every stage. The Government has a role in ensuring employers understand their responsibilities under Equalities Legislation and monitoring to ensure these responsibilities are being met.
- 5.8. Macmillan are calling on the Government to ensure employers understand and are meeting their legal duties to their employees with cancer in the context of COVID-19, including the protections under Equalities legislation. This includes making 'reasonable' adjustments – which can include working from home, undertaking alternative tasks or working temporarily reduced hours – wherever possible. The Government should set out how it will enforce these measures if necessary.
- 5.9. The Government should extend the Job Retention Scheme for clinically vulnerable people so that employers can continue to offer furlough to people who are unable to return to work safely, whether they have been furloughed before or not.
- 5.10. Guidance for employers must also be clarified and strengthened to ensure employers are meeting their legal responsibilities to support people with cancer to remain in work.
- 5.11. This guidance should ensure employers offer furlough to people who are shielding or vulnerable if other options such as reasonable adjustments to support them to return to work safely have been exhausted, so that no-one has to make a choice between their health and making ends meet.
- 5.12. We are concerned that many people with cancer have not been furloughed by their employer but instead have had to claim SSP of £95.85 a week and seen their income drop drastically as a consequence. The Government should not withdraw eligibility for Statutory Sick Pay (SSP) from people who may be required to continue to shield beyond 1st August.
- 5.13. As the Government encourages people to return to work, many people with cancer, and those who live with someone with cancer, will face anxiety around whether this is safe. The Government must do more to ensure that these people are not faced with an impossible choice between protecting their health and paying their bills.
- 5.14. Guidance needs to be clarified and strengthened so that employers understand their legal duties to support people with cancer to remain in work under Equalities legislation, and that they can continue to offer furlough to people who are vulnerable or shielding.

¹⁸ ONS, Coronavirus and shielding of clinically extremely vulnerable people in England: 28 May to 3 June 2020
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/coronavirusandshieldingofclinicallyextremelyvulnerablepeopleinengland/28mayto3june2020#employment-situation-of-clinically-extremely-vulnerable-people>

5.15. Guidance also needs to recognise the risks presented to shielded and vulnerable people by household members returning to work and encourage employers to also offer furlough to people who live with someone who is vulnerable or shielding.

6. Financial Impact

6.1. Alongside the physical and emotional impact of cancer, a diagnosis also brings the risk of financial hardship. Macmillan's research has shown that four in five people with cancer are on average, £570 a month worse off as a result of their diagnosis.¹⁹ Among the groups hardest hit were people under the age of 60; those in work at the time of diagnosis; people with dependent children and; those owning their homes with a mortgage. For the 30% of people who lost income, this was, on average £860 a month.

6.2. The social security system is a vital safety net for many people with cancer who face a financial impact from their diagnosis. Evidence emerging from Macmillan's welfare advisers indicates that the benefits system is not coping with current demand. At the start of the crisis a third of the calls to Macmillan helplines were related to COVID-19.

6.3. It is disappointing that the Government has not taken steps to remove the 5-week wait for Universal Credit (UC). Many people with cancer face a financial shock at the point of diagnosis and waiting 5 weeks for their first UC payment puts them at risk of additional stress, anxiety and hardship.

6.4. People with mortgages are among the hardest hit financially by a cancer diagnosis. Support with getting temporary mortgage forbearance is one of the issues most frequently dealt with by Macmillan's Financial Guidance Service.

6.5. Some people with cancer were unable to access the measures, either due to prior financial difficulty or simply being unable to speak to their lender, stuck at the back of a call queue. Automation and online processing to cope with the scale of operational demand meant that many of those who did access the 'off the shelf' COVID-19 package had no contact with their lender and hence did not receive any personalised guidance or support.

6.6. As a result, Macmillan Financial Guidance Service has seen issues ranging from misunderstandings and confusion over whether the deferrals would need to be repaid at all, or when and how this would happen including the potential for payments to increase or there being a significant additional cost in the longer term. Because the measures aligned with COVID-19, not cancer journeys, there is now a risk that someone's mortgage payments will increase at a time of financial strain. People living with cancer may once again be 'lost' among the 2 million borrowers²⁰ who have taken payment holidays that will also be seeking support as these come to an end.

6.7. We are particularly concerned that it now appears the initial commitments and efforts to ensure that the relief measures would not damage credit files will be undermined. We understand that lenders are now likely to use other data sources and new technologies such as open banking to identify customers who took them, and to use this in future affordability assessments.

¹⁹ Macmillan Cancer Support, *Cancer – A costly Diagnosis*, 2019 https://www.macmillan.org.uk/_images/cancer-a-costly-diagnosis-report-2019_tcm9-354186.PDF

²⁰ Latest figures from UK Finance show 1.86 million mortgage payment holidays have been issued as of 28 May 2020 – equivalent to one in six mortgages. <https://www.ukfinance.org.uk/press/press-releases/lenders-commit-to-ongoing-support-for-mortgage-borrowers>

- 6.8. The FCA recently stated that: “Going forward we must not forget those consumers with vulnerabilities or conditions unrelated to coronavirus, including those with cognitive impairment or people with a diagnosis of cancer”.²¹
- 6.9. The Government must ensure that cancer does not become the ‘forgotten C’ of financial impact and recognise the dual impact on people living with cancer. To achieve this The FCA should be directed to issue guidance outlining expectations for how firms should appropriately support people with cancer and other pre-existing vulnerabilities as the temporary relief measures are withdrawn
- 6.10. Prior to the pandemic, people living with cancer and other disabilities often struggled to access affordable and appropriate protection insurance. Macmillan is a member of the Access to Insurance Working Group convened by the Cabinet Office’s Disability Champion for the insurance sector which aims to address these.
- 6.11. At the outset of the crisis, many insurers stopped requesting medical reports from GPs in order to ease pressure on the NHS frontline.²² Thousands of consumers with cancer and other disabilities requiring medical underwriting were effectively locked out of the market. We are now hearing reports that, in response to anticipated health and societal impacts of COVID-19, the industry is beginning to decline cover or increase the cost for certain groups, sometimes using blanket underwriting approaches where there is limited or no evidence that an individuals’ risk is increased by COVID-19. It is unclear how this is objectively justifiable. We do know that the situation is likely to worsen without intervention.

22/07/2020

²¹ How has COVID-19 affected vulnerable consumers?, Financial Conduct Authority, June 2020

<https://conversation.which.co.uk/money/vulnerable-consumers-sheldon-mills-fca/>

²² This was also set out as part of The Association of British Insurers’ COVID-19 ‘Protection Pledges’

<https://www.abi.org.uk/products-and-issues/choosing-the-right-insurance/income-protection/pledges/>