

Dear Ms Moran,

RE: Invitation to give evidence: APPG on Coronavirus

Thank you for the opportunity to give evidence to the All-Party Parliamentary Group (APPG) on Coronavirus, on the impact the pandemic has had on breast cancer.

Around 55,000 women and 370 men are diagnosed with breast cancer every year in the UK. Breast cancer is the most common cancer in women in the UK, with one in seven women in the UK developing it in their lifetime. From those, there are an estimated 35,000 people currently living with secondary breast cancer (also known as stage four, metastatic or advanced) in the UK. Once the cancer spreads, it can no longer be cured. Sadly, around 11,500 people still die from breast cancer every year in the UK, almost all from secondary.

We are sharing with you our two most recent reports, '[Press Play: Getting and Keeping Breast Cancer Services Back on Track](#)' (published October 2020) and '[The Unsurvivors Report](#)' (published October 2019), both of which provide the necessary background information on our main areas of concern: early diagnosis, secondary breast cancer, access to Clinical Nurse Specialists (CNSs) and research. We will address in this letter all the questions asked in the e-mail:

1. What has been the impact of the pandemic?
2. What support has been provided by the Government?
3. What could have been done differently?
4. What lessons must urgently be learned?
5. What is needed as we head into the next phase of the pandemic?

(1) What has been the impact of the pandemic?

Coronavirus is the biggest crisis that breast cancer has faced in decades. At the height of the pandemic, we saw a big drop in the number of people being referred to see a specialist with suspected breast cancer. Screening services were paused. Recruitment to many clinical trials was paused. And while many patient's treatment continued unchanged other patients saw delays and cancellations to their treatment alongside changes to the support they received. This has caused huge levels of anxiety - particularly for patients with incurable secondary breast cancer and their loved ones.

Breast Cancer Now's world-class research and life-changing community support services are here for anyone affected by the disease, but they have been deeply affected. And the fundraising that powers them has also been hit hard, too.

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Impact on early diagnosis of breast cancer:

- In England, between March and July 2020 there were over 95,000 fewer referrals by a GP for tests compared with 2019¹. We estimate that across the UK there is likely to have been nearly 107,000 fewer breast cancer referrals².
 - NHS England cancer waiting times data from August 2020 also shows that the two weeks wait targets for people referred with suspected breast cancer or breast symptoms was not met and decreased from July 2020³.
 - Data for September 2020 will be published on 12 November.
- The breast screening programmes were effectively paused in March. We estimate that a backlog of nearly a million women built up across the UK prior to programmes restarting⁴.
- The expected increase in referrals and backlog of women waiting for breast screening will lead to an increase in demand for diagnostic and imaging services in the coming months, but the workforce in these services was already stretched before the pandemic:
 - A quarter of trusts and health boards across the UK have at least one vacant breast radiologist role, and vacancies are set to increase as a quarter of breast radiologists are expected to retire over the next five years⁵.

Impact on Secondary Breast Cancer

- During the pandemic, some patients with both primary and secondary breast cancer had their chemotherapy or targeted treatments changed or temporarily paused, primarily to protect their immune systems.
 - Data from NHS England suggests that in April 2020 the number of people starting chemotherapy for breast cancer fell to 61% of levels in April 2019. By June this had returned to 92% of 2019 levels⁶.
- From our recent survey⁷, of those whose drug treatment was affected as a result of the pandemic, 39% were worried changes would impact on the effectiveness of their drug treatment, with this being a bigger worry for secondary patients.

1 Monthly Provider Based Data and Summaries, Cancer Waiting Times, NHS England. Available at:

www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/monthly-prov-cwt/

2 Estimate based on cancer waiting times data in England and Wales. For Scotland and Northern Ireland the average percentage drop in referrals in England between March and July 2020 was applied to referrals between March and July 2019.

3 We respond to NHS England breast cancer waiting times: August 2020, Breast Cancer Now, October 2020.

Available at: <https://breastcancer.org/about-us/media/statements/we-respond-nhs-england-breast-cancer-waiting-times-august-2020>

4 Estimate based on the average number of women screened per month, and the approximate length of time the screening programme was suspended, in each part of the UK.

5 Clinical Radiology: UK workforce census 2019, Royal College of Radiologists, April 2020. Available at: www.rcr.ac.uk/system/files/publication/field_publication_files/clinicalradiology-uk-workforce-census-2019-report.pdf

6 Data provided by NHS England and NHS Improvement.

7 Press Play: Getting and Keeping Breast Cancer Services Back on Track, Breast Cancer Now, October 2020.

Available at: https://breastcancer.org/sites/default/files/bcn_untilthingschange_final_30.09.20.pdf

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- Nearly half (47%) of patients felt that changes to their drug treatment increased their anxiety, with 41% stating the changes had a negative impact on their emotional and mental wellbeing.
- Through our Helpline and our insight work we found that secondary breast cancer patients in particular report concerns they may die sooner due to changes to their care or the suspension of clinical trials⁸.
- Guidance was developed on how patients should be prioritised for drug treatment if this became necessary. Patients having noncurative treatment, such as those with secondary breast cancer, were generally given a lower priority than those having curative treatment⁹. The extent to which this guidance was used in practice is unclear.
- It is essential that the needs of secondary breast cancer patients are identified and addressed in the cancer recovery plans being developed, including recognising the importance of drug treatment for these patients. However, it is unclear how this will be achieved since data collection on secondary patients is irregular.
 - Although in England it has been mandatory for Hospital Trusts to collect data on new diagnoses of metastatic breast cancer since 2013, this has not routinely happened in practice.
 - Our Freedom of Information request sent in 2018 found that 40% of trusts and health boards were unable to say how many patients with secondary breast cancer were in their care¹⁰.

Impact on access to support from a Clinical Nurse Specialist (CNS)

- The pandemic and resulting changes to treatment and care have been a real source of anxiety for many people with breast cancer. Whilst the majority of respondents that accessed support did so through a clinical nurse specialist (CNS), 41% of respondents to our survey felt they had less contact with their CNS during the coronavirus outbreak¹¹.
- Access to a CNS can make a big difference to the way people experience their care. This is particularly important for patients with secondary breast cancer who will be on lifelong treatment and have complex emotional and support needs.

8 Thousands of women with incurable breast cancer ‘fearing for survival’ amid delays to treatments, scans and access to trials, Breast Cancer Now, May 2020. Available at: <https://breastcancernow.org/about-us/media/press-releases/thousands-women-incurable-breast-cancer-%E2%80%98fearing-survival%E2%80%99-amid-delays-treatment-scans-access-trials>

9 Clinical guide for the management of non-coronavirus patients requiring acute treatment: cancer, NHS England, March 2020. Available at www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/specialty-guideacute-treatment-cancer-23-march-2020.pdf and Coronavirus (COVID19); national guidelines for cancer treatment, Scottish Government, April 2020. Available at: www.gov.scot/publications/coronavirus-covid-19-clinical-guidelines-forcancer-treatment/

10 Breast Cancer Care (2018), Secondary support package: Evidence report. Available at:

https://breastcancernow.org/sites/default/files/secondary_support_package_evidence_reportjan2019.pdf

11 Press Play: Getting and Keeping Breast Cancer Services Back on Track, Breast Cancer Now, October 2020.

Available at: https://breastcancernow.org/sites/default/files/bcn_untilthingschange_final_30.09.20.pdf

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- However, in a Breast Cancer Now survey of secondary breast cancer patients in 2019 only 30% said they regularly saw a CNS, and only 65% said their CNS had enough time to spend with them¹².
- A Breast Cancer Now survey of CNSs in early 2020 found that only 35% felt that they have enough time to offer each secondary breast cancer patient the opportunity to discuss their wider concerns and needs in the weeks following diagnosis, and even less (31%) have the time to offer this as treatment changes or the cancer progresses.
- There was already a shortage of CNSs before the pandemic. Our survey of CNSs found that only one in three believed their hospital had enough specialist nurses to give secondary breast cancer patients the support and care they need, with 82% saying this was because there are not enough nursing posts.
 - In common with other parts of the workforce, many CNSs were redeployed elsewhere in the NHS during the peak of the pandemic. For example, over 400 Macmillan NHS professionals including Macmillan funded CNSs were redeployed¹³.

Impact on breast cancer research

- Breast cancer research gives hope for the future by discovering how to prevent breast cancer, save lives and help people to live well with the disease. Patients rely on this hope, but the impact of the pandemic on funding has been too great.
 - Members of the Association of Medical Research Charities (AMRC), who fund half of publicly funded medical research nationally, are planning an average 41% decrease in research spend in the 2020/21 financial year¹⁴.
- Like many other medical research charities, the research that Breast Cancer Now funds has been impacted by the estimated drop in our income.
 - Though our long-term research will continue, we had to reduce the amount of funding to the Breast Cancer Now Toby Robins Research Centre, Tissue Bank, Generations Study and King's College London Unit by at least 30%.
 - We also cancelled our latest round of project grants and PhD studentships.
 - Cuts to research may in the long-term lead to charities losing the capacity they have built in their research areas, including being unable to support the next generation of researchers.

12 The Unsurvivors, Breast Cancer Now, October 2019. Available at: breastcancernow.org/sites/default/files/bcn_report1_1019v2_-_final_22.11.19_0.pdf

13 Written evidence submitted by Macmillan Cancer Support for Health and Social Care Committee's inquiry on Delivering Core NHS and Care Services during the Pandemic and Beyond, Macmillan Cancer Support. Available at: committees.parliament.uk/writtenevidence/4582/pdf/

14 Life Sciences-Charity Partnership Fund: An economic case for targeted support for charity-funded research, AMRC. Available at: https://mcusercontent.com/3636b25c2bfb83fcae0b886a2/files/ec4bc2d2-94b2-4f19-b512-2761c76c1ae8/Briefing_Life_Sciences_Charity_Partnership_Fund_An_economic_case_for_targeted_support_for_charity_funded_research_October_2020.pdf

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(2) What support has been provided by the Government?

Government support has mainly focused on improving early diagnosis, but without fully addressing the enormity of the crisis facing the cancer workforce. The topics of secondary breast cancer and research funding have so far not been addressed.

On improving early diagnosis of breast cancer

- The NHS Long-Term Plan (LTP), published in January 2019, sets a new ambition that, by 2028, the proportion of cancers diagnosed at stages 1 and 2 will rise from around half now to three-quarters of cancer patients.
- Screening services in England have now resumed.
 - Ahead of a second wave and further restrictions, the Government declared it has advised that screening services should continue as contracted, including continuing actions to support full restoration, and the expectation that screening staff should not be diverted and building facilities should not be repurposed¹⁵.
- Among the strategies the Government has declared to be taking to improve early diagnosis of breast cancer, are:
 - Launching NHS England’s ‘Help Us Help You’ campaign to encourage the public to continue to access cancer services, including breast screening.
 - Making funding available to support the adaptation of mobile screening units to ‘enhance their safe use and so maximise the number of units available to screen women’¹⁶.
 - Prioritising increasing the number of urgent cancer referrals, to ‘reduce the number of patients waiting longer than 62 and 104 days for treatments or diagnostics, and ensuring capacity is in place for the winter’¹⁷.
 - Working with Cancer Alliances ‘to ensure sufficient diagnostic capacity in covid-19-secure environments, through independent sector facilities and the development of community diagnostic hubs and rapid diagnostic centres’¹⁸.
 - Encouraging providers ‘to use methods such as text messaging to remind women about their breast screening invitation and encourage them to attend’¹⁹ and to consider the needs of the local breast screening population to ‘reduce health inequalities’²⁰.
- The NHS People Plan for 2020/21 in England, published in July, included a commitment to train 450 reporting radiographers and invest in clinical radiology training²¹. A full NHS People Plan is expected after the Government’s Spending

15 UIN 102711, tabled by Rosie Cooper MP on October 13 for the Department for Health and Social Care.

16 UIN 100905, tabled by Dame Diana Johnson MP on October 8 for the Department for Health and Social Care.

17 Ibid.

18 Answer to 12 October debate on ‘Queen Mary’s Hospital: Urgent Care Services’ by the Minister for Health Edward Argar MP.

19 UIN 100906, tabled by Dame Diana Johnson MP on October 8 for the Department for Health and Social Care.

20 UIN 101307, tabled by Tanmanjeet Dhesi MP on October 9 for the Department for Health and Social Care.

21 We are the NHS: People Plan 2020/21 – action for us all, NHS England, August 2020. Available at: www.england.nhs.uk/wp-content/uploads/2020/07/We_Are_The_NHS_Action_

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Review in November, when there would be clarity on the investment available for education and training for the workforce.

On addressing Secondary Breast Cancer issues

- There has not yet been a direct answer from the Government on what they are doing to specifically address secondary breast cancer issues, with answers to tabled questions at times not specifically addressing secondary breast cancer issues²²²³²⁴, or still unanswered as of November 10²⁵.
- Recently, the Government has stated that ‘there are no plans in place for a dedicated audit into national secondary breast cancer’²⁶. It also stated that ‘the number of reported cases is accepted as being significantly below the estimated number of secondary breast cancers’ and that the ‘National Cancer Registration and Analysis Service is working closely with cancer charities to improve data collection and submission by hospital trusts’²⁷²⁸²⁹. However, Breast Cancer Now is not familiar with any work between the NCRAS and charities on improving secondary breast cancer data collection.

On increasing CNS support

- The NHS Long-Term Plan commits that by 2021, ‘all patients, including those with secondary cancers, will have access to the right expertise and support, including a Clinical Nurse Specialist or other support worker’. The Government has recently confirmed that this remains their ambition³⁰. However, we are unsure how success will be measured without data collection on secondary breast cancer.
- The recent NHS People Plan for 2020/21 in England included 350 training grants for nurses to become cancer CNSs and chemotherapy nurses³¹. A long-term NHS People Plan, detailing how the Government will recruit and train more CNSs to meet the current and long-term needs of people living with breast cancer was expected for after the Government’s Spending Review in the autumn, when there would be clarity on the investment available.

For_All_Of_Us_FINAL_24_08_20.pdf

22 UIN 83972, tabled by Zarah Sultana MP on September 1 for the Department of Health and Social Care.

23 UIN 84742, tabled by Zarah Sultana MP on September 3 for the Department of Health and Social Care.

24 UIN 61566, tabled by Bambos Charalambous MP on June 18 for the Department of Health and Social Care.

25 UIN 109744, tabled by Jane Hunt MP on October 30 for the Department of Health and Social Care.

26 UIN 102752, tabled by Caroline Lucas MP on October 12 for the Department of Health and Social Care.

27 UIN 107716, tabled by Liz Twist MP on October 22 for the Department of Health and Social Care.

28 UIN 107640, tabled by Caroline Nokes MP on October 22 for the Department of Health and Social Care.

29 UIN 105411, tabled by Dr Lisa Cameron on October 19 for the Department of Health and Social Care.

30 Answer to Health Oral Question asked by Kim Johnson MP on October 6 by the Parliamentary Under-Secretary of State for Health and Social Care Jo Churchill MP.

31 We are the NHS: People Plan 2020/21 – action for us all, NHS England, August 2020. Available at:

www.england.nhs.uk/wp-content/uploads/2020/07/We_Are_The_NHS_Action

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On addressing research funding issues

- The Government has provided a £750 million support package for UK charities during the coronavirus outbreak³². No specific support package for medical research charities has been announced.

(3) What could have been done differently?

While the NHS has taken extensive steps to minimise the impact of the pandemic, there inevitably have been pauses and delays in treatment and diagnosis. We cannot afford to pause again. Which is why we welcome the Government's assurance that it will not stop screenings during the winter and their initiatives to drive up referrals.

However, their initiatives do not fully address the workforce needed to clear the backlog and improve services into the future. While we were pleased to see investment in recruiting and retaining more staff next year, we now need a long-term vision and plan to ensure that the breast cancer workforce also has enough resource and support beyond the coming year. It is crucial the Government uses the opportunity of the Spending Review to send a strong signal of its commitment to invest in the NHS staff that people affected by cancer rely on. Following this, we hope to see a comprehensive NHS People Plan.

As mentioned previously, guidance also suggested how patients should be prioritised for drug treatment if this became necessary. Patients having noncurative treatment, such as those with secondary breast cancer, were generally given a lower priority in the guidance than those having curative treatment³³. This was hugely concerning, and we raised this with governments and the NHS who reiterated the importance of decisions being made on an individual basis according to the risks and benefits of treatment. However, the extent to which this guidance was used in practice is unclear. It is essential that the needs of secondary breast cancer patients are identified and addressed in the cancer recovery plans that are being developed, including recognising the importance of drug treatment for these patients.

(4) What lessons must urgently be learned?

What we have seen and heard about the impact of coronavirus on breast cancer, including through our survey and discussions with healthcare professionals, suggests there are many challenges that need to be addressed moving forward. The breast cancer workforce will be critical to addressing these challenges. The imaging and diagnostics workforce was

32 Financial support for voluntary, community and social enterprise (VCSE) organisations to respond to coronavirus (COVID-19), Department for Digital, Culture, Media & Sport, May 2020. Available at: <https://www.gov.uk/guidance/financial-support-for-voluntary-community-and-social-enterprise-vcse-organisations-to-respond-to-coronavirus-covid-19>

33 Clinical guide for the management of non-coronavirus patients requiring acute treatment: cancer, NHS England, March 2020. Available at www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/specialty-guideacute-treatment-cancer-23-march-2020.pdf and Coronavirus (COVID19); national guidelines for cancer treatment, Scottish Government, April 2020. Available at: www.gov.scot/publications/coronavirus-covid-19-clinical-guidelines-forcancer-treatment/

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stretched before the pandemic. Clinical nurse specialists did not have enough time to spend with patients with secondary breast cancer. Further action is urgently needed in the short and longer-term across the UK to ensure there is an appropriately resourced workforce.

As the number of referrals to see a cancer specialist continues to recover and the breast screening programme restarts there is likely to be an influx in demand for imaging and diagnostics which threatens to overwhelm these services. It is vital that the recovery plans being developed by governments and the NHS across the UK set out how this expected surge in demand will be managed so people are diagnosed and start treatment for their breast cancer as soon as possible. Without this recovery plans could be undermined and we risk failing to achieve broader ambitions on early diagnosis, treatment and care.

The pandemic and resulting changes to treatment and care have also been a real source of anxiety for many people with breast cancer. Whilst the majority of respondents that accessed support did so through a clinical nurse specialist (CNS), many felt they had less contact with them during this period. It is vital that cancer recovery plans being developed across the UK ensure that patient's care and support needs are being met during this period.

We recognise the recent announcement that the Spending Review will be for one year only, apart from NHS and schools' resource settlements. The full NHS People Plan, and the Government's successful recovery of cancer services is dependent on long-term funding being allocated, so it is vital that Health Education England is included within the multi-year resource settlement.

Similarly, the lack of significant progress on improving data collection on secondary breast cancer means that we now have a gap in reliable information on the impact of the pandemic and the success of its recovery for one of the most clinically vulnerable groups to Covid-19, and whose survival relies on their uninterrupted access to treatment and research. It is vital the Government acknowledges secondary breast cancer patients and no longer delays progress on data collection.

The pandemic has also resulted in some positive changes. The NHS moved quickly to issue guidance on safely diagnosing and treating cancer. Some changes to drug treatment and radiotherapy – which benefit both patients and the NHS – were implemented more quickly than they would otherwise have been. And for some patients, virtual consultations have freed up time and removed the anxiety of going to hospital during this period. We need to make sure that these positive changes are carried forward. For example, in conversations with secondary breast cancer patients they have pointed to the speed with which trials for coronavirus have been set up and are keen for the lessons from this to be applied to setting up clinical trials for cancer and other health conditions.

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(5) What is needed as we head into this next phase of the pandemic?

It is crucial that breast cancer services and research are restored to where they were before the pandemic, and that the ambitions made in the NHS Long-term plan are achieved. This will not be possible without investment from the Government in the upcoming Spending Review in the autumn, including:

- Additional funding for the breast cancer workforce, in particular investment in: Clinical Nurse Specialists (CNS) to support those with incurable secondary breast cancer so that they have access to the care and support they need; and the imaging and diagnostic workforce, to address the expected backlog as a result of COVID19 and longer term capacity issues.
- Funding for a National Secondary Breast Cancer Audit covering diagnosis, treatment, and access to support, to provide the missing insight that is desperately needed to ensure the NHS can meet the needs of those living with secondary breast cancer.
- A commitment to support a Life Sciences Charity Partnership Fund to mitigate the impact of the pandemic and ensure continuity of charity funded research, as supported by the AMRC. A suggested £310 million of funding from government in 2020/21 has been requested to bridge the projected shortfall in sector spend. This funding would be matched by funding from charities to ensure overall sector investment is maintained.

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